DOCUMENT RESUME

ED 405 153 RC 020 931

AUTHOR	Fowler, LaDonna; And Others
TITLE	American Indian Approaches to Disability Policy: Establishing Legal Protections for Tribal Members with Disabilities: Five Case Studies.
INSTITUTION	Montana Univ. Affiliated Rural Inst., Missoula.
SPONS AGENCY	National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE	Dec 96
CONTRACT	H133G30031-95
NOTE	84p.; Diskette not available from EDRS.
AVAILABLE FROM	Research and Training Center on Rural Rehabilitation, Rural Institute on Disabilities, 52 Corbin Hall, The University of Montana, Missoula, MT 59812.
PUB TYPE	Reports - Research/Technical (143)
EDRS PRICE	MF01/PC04 Plus Postage.
DESCRIPTORS	American Indian Culture; *American Indian Reservations; American Indians; Case Studies; *Cultural Influences; *Disabilities; Disability Discrimination; Federal Indian Relationship; Focus Groups; Models; *Needs Assessment; *Policy Formation; *Tribal Government; Tribes
IDENTIFIERS	Americans with Disabilities Act 1990

ABSTRACT

This report presents case studies of five American Indian tribes that employed the Tribal Disability Actualization Process for considering disability legislative and policy issues. The first section reviews the history of the relationship between Indian nations and the United States, and addresses the demography of disability among American Indians as well as cultural views of disability among tribes. The American Indian Disability Legislation (AIDL) Project aimed to create a process for tribes to use in developing disability legislation that is consistent with the principles established by the Americans with Disabilities Act, but also respects tribal sovereignty and cultural diversity. The Tribal Disability Actualization Process includes identifying and developing key leadership contacts, seeking tribal authorization, holding cultural discussions and focus groups, and developing and implementing policy recommendations. Case studies of the Flathead Reservation (Montana), Navajo Reservation (Arizona), Pine Ridge Reservation (South Dakota), Fort Peck Reservation (Montana), and the Nez Perce Reservation (Idaho) examine implementation of this process and summarize focus group discussions and recommendations for policy development. Major issues included traditional beliefs about disabilities, public awareness education, public accommodations and access, employment, transportation, tribal jurisdiction over services, and training needs. This report concludes that the use of the Tribal Disability Actualization Process successfully brought together a wide range of concerned tribal members who identified important disability issues and generated recommendations that led to changes in tribal government practices and policies. Appendices include resolutions of the National Congress of American Indians supporting the development of American Indian disability legislation and AIDL, a map of focus groups, and tribal amendments regarding disability policy. Contains a computer diskette and 15 references. (LP)

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ED 405 153

AMERICAN INDIAN APPROACHES TO DISABILITY POLICY

Establishing Legal Protections for Tribal Members with Disabilities: Five Case Studies

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AMERICAN INDIAN APPROACHES TO DISABILITY POLICY

Establishing Legal Protections for Tribal Members with Disabilities: Five Case Studies

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December, 1996

There is no word in the Nez Perce language for disability, only a word for weak mind (pel-pel). "Our grandfathers and aunts taught us acceptance. We were taught to respect and help anybody who needed help. This is how respect was taught .... We were told you should listen to the disabled. Learn from them and respect them. We were taught that it was important to respect the disabled for whom they were and include them as equals. Our aunts told us that we should not make fun of them or talk about them because the spirits could make the same thing happen to you."

Nez Perce Focus Group Participant

Acknowledgement

This work was supported by a grant from the National Institute on Disability and Rehabilitation Research (#H133G30031-95), Office of Special Education and Rehabilitative Services, U.S. Department of Education. The American Indian Disability Legislation Project is a project of the Montana University Affiliated Rural Institute on Disability and The University of Montana – Missoula. The opinions expressed are those of the authors and do not reflect the position of the agency.

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Executive Summary

The passage of the Americans with Disabilities Act (ADA) has the potential to improve the lives of all people with disabilities residing in the U.S. Yet, American Indians with disabilities living on tribal lands may not benefit from this law because it specifically excludes Indian tribes from its requirements.

This report describes a process, endorsed by the National Congress of American Indians employed by five groups of tribes for considering legislative and policy issues. The history of the relationship between the Indian Nations and the United States, the demography of disability among American Indians and the cultural views about disability among tribes is presented.

The major goals of the American Indian Disability Legislation (AIDL) Project was to develop more understanding of the concept of and reaction to disability among American Indians, and to create a process for tribes to consider their own disability legislation. In an effort to accomplish these goals, the Project developed and tested methods for fostering the adoption of disability legislation by American Indian tribes that is consistent with the principles established by the Americans with Disabilities Act, and is respectful of tribal sovereignty and cultural diversity.

The project was divided into two major stages. The first was designed to assess the status of tribal policies and attitudes toward disability through a survey of 143 tribal governments. The second was to develop and field test a process for tribes to use in considering their own disability policy and legislation.

Currently, only about 6% of the respondents indicated their tribal governments were very familiar with major disability legislation, including Sections 503 and 504 of the Rehabilitation Act of 1975, IDEA and the ADA. One tribe of the 143 surveyed has reported adopting the ADA. Several others have said that while they have discussed access and employment issues, they do not have written policy. As such, disability legislation among the tribes remains an unaddressed issue of importance.

The rate of disability among American Indians in 1995 was approximately 22.6%. However, most tribes do not currently recognize the need to provide funds to deal with disability issues. Only 13% of tribes have a line item in their budget for disability issues.

In 1994, most tribes did not appear ready to establish disability legislation. However, 110 of 143 of the survey respondents (74%), said they believe their tribal government would be interested in participating as a focus group for establishing disability legislation within their tribe.

The second phase of the AIDL Project centered on focus group development and implementation. Project staff contacted five sites, representing 10 tribes of three cultural/geographical regions, and were invited to present the process.

The Tribal Disability Actualization Process model was based on work done by Brown (1986). Its major steps included identifying and developing key leadership contacts, seeking tribal authorization, holding cultural discussions and focus groups, and developing and implementing policy recommendations.

Two handbooks, developed by AIDL Project staff, helped focus groups develop disability legislation. *How to Hold a Successful Focus Group Meeting* was written as an aide to facilitate the meeting process in a culturally-sensitive manner. *A Guide to Developing Disability Policies on American Indian Reservations* was written as a tool to enable the focus groups to seek their own solutions to disability issues. A number of handouts, including *Disability Laws*, *How Have American Indian Tribes Addressed Disability Issues?* and *Ruralfacts: American Indians and Disability*, were also written to facilitate the process.

The five case studies show that, in a surprisingly short period of time covered by this report, the use of the Tribal Disability Actualization process brought significant impact. It brought together a wide range of concerned tribal members, helped them identify many disability issues of importance and develop numerous suggestions for change. Each of the groups developed commitment and met repeatedly. Further, they have continued to meet since the formal end of this project. Their efforts have led to several policy and program changes consistent with the spirit f the ADA but respectful of tribal culture and sovereignty. As such, this study offers evidence of the effectiveness of a self-directed approach for tribes to develop disability legislation.

The experience demonstrates that tribal governments can and will develop disability legislation and policy consistent with the ADA without the U.S. Government's intervention. In fact, these experiences show a high level of concern and commitment among leaders when disability issues are brought to their attention by tribal members.

This is an approach to community development that is truly a rural response. It may provide a method of universal application because it offers the members of any community, no matter what size, the opportunity to review problems and develop solutions that meet their unique circumstances.

The tribes that participated in the process have made significant headway toward educating their members about the needs of Indian people with disabilities. They have also recognized that their efforts must be consistent and on-going, and that funding and enforcement are key issues.

Most tribes lack the financial resources to mount a systematic effort to build tribal disability legislation. State governments have little responsibility and less authority on

reservations. While some foundations have interest in supporting tribal development, they tend to focus narrowly on special issues or support only a few tribes.

Only the Federal government has the combination of authority, resources and responsibility in this area. Unfortunately, no federal agency has the duty to assist tribes in addressing this gap in disability law and policy. This situation must be clarified if American Indians with disabilities are to enjoy the same protections as their neighbors.

Table of Contents

Introduction 1

A Brief History of U.S. Laws Applied to American Indians 2
Disability in Indian Country 4
Culture and Disability 5

The American Indian Disability Legislation Project 5
- General Approach 5
- National Survey of Tribal Governments 6

Tribal Disability Actualization Process 8
- Procedures 8
- Identifying Key Leadership Contacts 9
- Tribal Authorization 9
- Focus Groups and Cultural Discussions 9
- Policy Development, Recommendations and Impact 11

Results 11

- Flathead Reservation 13
  - Initial Contact and Tribal Authorization 13
  - Focus Group 14
    - Cultural and Personal Beliefs 14
    - Public Accommodations and Access 15
    - Employment 17
    - Transportation 18
    - Open Reservation Considerations 19
    - Public Awareness and Education 20
  - Policy Development, Recommendations and Impact 20

- Navajo Reservation 23
  - Initial Contact and Tribal Authorization 23
  - Focus Group 23
    - Beliefs - Traditional and Tribal 23
    - Personal Care Issues 27
    - Dealing with Disability 29
  - Policy Development, Recommendations and Impact 32

- Pine Ridge Reservation 33
  - Initial Contact and Tribal Authorization 33
  - Focus Group 34
    - Public Awareness and Education 34
  - Policy Development, Recommendations and Impact 35

Fort Peck Reservation 37
Initial Contact and Tribal Authorization 37
Focus Group 37
Cultural and Personal Beliefs 37
Public Accommodations and Access 41
Employment 42
Transportation 42
Policy Development, Recommendations and Impact 42

Nez Perce Reservation 43
Initial Contact and Tribal Authorization 43
Focus Group 43
Cultural and Personal Beliefs 43
Public Accommodations and Access 47
Employment 48
Transportation 49
Policy Development, Recommendations and Impact 50

Discussion 52

References 57

Appendices 59

Table of Tables

Table 1: Participating Tribes and Their Populations 11
Table 2: Synopsis of Views Expressed and Issues Discussed 15
Table 3: Open Reservation Considerations 18

AMERICAN INDIAN APPROACHES TO ESTABLISHING DISABILITY POLICY:

LEGAL PROTECTIONS FOR TRIBAL MEMBERS WITH DISABILITIES

FIVE CASE STUDIES

The passage of the Americans with Disabilities Act (ADA) has the potential to improve the lives of all people with disabilities residing in the U.S. Yet, American Indians with disabilities living on tribal lands may not benefit from this law because it specifically excludes Indian tribes from its requirements. As Elizabeth Bazan, writing for the Congressional Research Service, states,

> "In general, civil rights statutes are often written in comprehensive language and normally are read broadly to accomplish their purposes. On the other hand, when Congress enacts a general federal law, which does not, by its own terms, expressly address Indians or Indian tribes, there is often considerable doubt as to whether such legislation applies to those Indians or Indian tribes. This seeming dilemma flows in large part from the unique relationship between the Indian tribes and the United States, and the rules of statutory construction which result therefrom." (Bazan, 1991).

In analyzing the potential application of the ADA or its various provisions to tribes, Bazan concludes, "...its ultimate resolution will rest in the hands of the courts." This conclusion assumes, however, that tribes do not want or will not accept nor implement the principles of the ADA voluntarily. Unfortunately it also assumes that tribes do not care about the concerns or needs of their members with disabilities, and that tribes will usually resist and reject ideas that may improve their lives. It is, in essence, based on a legal model, with a long history of confrontation. As such, it extends the century-long relationship between the Federal government and sovereign Indian nations through judicial conflict and confrontation.

An alternative perspective accepts tribes as sovereign nations. It recognizes that each tribe is bound by ties of blood, place and culture. It assumes that the leaders of each tribe and all its members care deeply about the character of their communities and the quality of life each enjoys. It recognizes that each tribe is committed to preserving its sovereignty, unique character and culture. It further assumes that innovations like the ADA represent ideas that, from the perspective of a tribe, may present both attractive opportunities as well as potential conflicts. Finally, it assumes that tribal members (both with and without disability) are best situated to weigh the pros and cons of ideas like the ADA and to accept, reject or modify them to best fit their communities.

This report describes a process, endorsed by the National Congress of American Indians (see Appendix A for specific resolutions),[1] employed by five groups of tribes for considering legislative and policy issues. In order to understand the purpose and goals of this approach, it is important to understand the history of the relationship between the Indian Nations and the United States. It is also important to understand the demography of disability among American Indians and the cultural views about disability among tribes.

A Brief History of U.S. Laws Applied to American Indians

In 1983 Vine Deloria and Clifford M. Lytle in *American Indians, American Justice* outlined six periods of federal Indian policy characterized by the impact of federal actions for trying to resolve the "American Indian problem." In the first phase, *Discovery, Conquest, and Treaty-making (1532-1828)*, Indian people were recognized "as legitimate entities capable of dealing with the European nations by treaty" and this became the basis for defining legal and political relationships among the parties.

The second period, *Removal and Relocation (1828-1887)*, began when the Indian Removal Act of 1830 was passed in order to move Indian people westward away from the approaching white civilization. During this period, various treaties began establishing reservations. The structure of these agreements was repeatedly violated by westward expansion, however, and these violations led to a period of *Allotment and Assimilation (1887-1928)*. During this period two-thirds of the reservation lands were reduced through allotment; jurisdiction over felony crimes became federal; the boarding school system was developed and other legislation was passed to promote assimilation.

The next phase, *Reorganization and Self-Government (1928-1945)*, brought an assessment of social and economic status of Indian people under the "Meriam Report." Recommendations from this report eventually became legislation. The Indian Reorganization Act of 1934 (IRA) passed to end the allotment policy and "to enable tribes to organize for their common welfare and to adopt Federally approved constitutions and bylaws." The constitutions were new and strange to most tribes and comprised a restructuring of their traditional ways.

Termination (1945-1961) was a period that saw the termination of several tribes by the passage of congressional resolutions and legislation. The reason for the termination policy was to reduce and eventually eliminate the Federal budget for Indian people.

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[1]The National Congress of American Indians, established in 1944, is the oldest and largest national Indian organization. It endeavors to sustain the rights of Indian people secured under Indian treaties and agreements with the United States, to develop better understanding of Indian people, to preserve Indian cultural values and to otherwise promote the welfare of Indian people.

Self-Determination (1961-Present) is a period in which many major pieces of legislation were enacted. "By the late 1960's, the policy of termination was largely regarded as a failure, and the assimilationist ideal began to fade" (Canby, 1988). The Indian Civil Rights Act of 1968 essentially imposed the basic requirements of the Bill of Rights that were previously not applicable to American Indians. Other laws enacted include: the Indian Education Act of 1972, the Indian Self-Determination and Education Assistance Act of 1975, and the establishment of the Senate Select Committee on Indian Affairs.

As this last period indicates, the trend of dealing with American Indians with an adversarial attitude has begun to change. President George Bush (Special Edition, 1991) reaffirmed the Federal government's recognition of tribal sovereignty. He stated, "... the existence and durability of our unique government-to-government relationship is the cornerstone of the Administration's policy of fostering tribal self-government and self-determination."

Because federal policy currently encourages tribal sovereignty and has moved toward helping tribes become autonomous, tribal governments are excluded from complying with much federal legislation, including the ADA. In general, most tribes are sovereign nations with legal authority and responsibility for their people and lands. The relationship of the various tribal governments to the government of the United States can be most simply understood as one based on negotiated treaties.

> "Indian Law has always been heavily intertwined with federal Indian policy, and over the years the law has shifted back and forth with the flow of popular and governmental attitudes toward Indians....At the risk of oversimplification, they may be reduced to four. First, the tribes are independent entities with inherent powers of self-government. Second, the independence of the tribes is subject to exceptionally great powers of Congress to regulate and modify the status of the tribes. Third, the power to deal with and regulate the tribes is wholly federal; the states are excluded unless Congress delegates power to them. Fourth, the federal government has a responsibility for the protection of the tribes and their properties, including protection from encroachments by the states and their citizens." (Canby, 1994).

This means that, under current Federal law, for the ADA to apply on tribal lands[2] either a separate negotiation must be conducted with each of the approximately 547 tribes currently recognized by the Federal government or the tribes must initiate the process for themselves. While this arrangement clearly allows the tribes to protect their cultures and values, it means that special efforts must be made to extend potentially good ideas to those on tribal lands who might benefit from them.

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[2]Tribal lands include federally recognized reservations, Alaska Native villages and tribal trust lands.

Tribal governments are as varied as the tribes, native villages and reservations they represent. Most tribes were severely damaged by white conquest and indigenous systems of government fell to federal management. Many tribes were unnaturally grouped on reservations. "The Indian Reorganization Act of 1934 provided that any tribe or tribes 'residing on the same reservation' had the right to organize and adopt a constitution ... the "new 'constitutional' tribes often included more than one ethnic tribe" (Canby, 1988). And while the new constitutions, designed by the Federal government, were adopted by many tribes, many other tribes rejected the provisions of the IRA outright.

Of the tribal governments that accepted the new constitutions, many have made significant changes to meet the needs of their people. For example, one tribe's government is comprised of 10 council members elected from districts that represent the four confederated tribes living on that reservation. They meet twice a week to manage the business of the tribe. Another tribal government has over 400 delegates representing a single tribe and is structured similarly to the U.S. Congress. They meet quarterly. The result is that with each tribal group or reservation a different approach to legislative change is needed. Disability policies must be fashioned with recognition of these disparate governmental structures.

Disability in Indian Country

Today, there are 1.9 million American Indians and Alaska Natives. About half live on or near one of the 547 state or federally recognized reservations. Most reservations are located in rural or remote areas, and all but two have populations of fewer than 10,000 Indian people (U.S. Census of Population, 1990).

Proportionately, the prevalence of disability among the American Indian population – especially those on tribal lands – is among the highest of any ethnic group in the country (U.S. Department of Education, 1987). Similarly, studies (e.g., Clay, Seekins & Cowie, 1990) have found that American Indians with disabilities experience both a higher rate and a greater severity of secondary conditions than do other groups. This may be attributed, in part, to American Indians' lack of access to services and information.

American Indian disability advocates also report that service providers (e.g., some Bureau of Indian Affairs [BIA] and Indian Health Service [IHS] offices, as well as private providers and businesses) do not have accessible facilities or services. Further, programs that advocate for such access on tribal lands are extremely rare (Clay, 1992).

Generally, non-Indian disability advocates have promoted access to facilities, services, employment and other social benefits through the passage and enforcement of laws, such as the ADA. Unfortunately, there are few data reported as to whether

such laws and regulations exist among the tribes or whether tribes even view these laws as potentially valuable or culturally relevant.

Culture and Disability

Applying the concept of disability to American Indian culture is an extraordinary challenge. First, disability is an idea familiar to Western culture but with no direct parallel in American Indian culture (Clay, 1992). A Navajo vocational rehabilitation counselor once said it would take a page and a half of words in the traditional Navajo language to capture the meaning of this one English word "disability." Acceptance and tolerance of many aspects of life including disability, are tenets for most American Indian people. Disabling conditions are accepted as a part of the person; as the way the Creator intended. The closest American Indian concept does not look at physical characteristics but views disability as disharmony of spirit. Breaking a tribal or sacred taboo, for many traditional American Indians, may cause a disharmony that manifests itself as a disability (Locust, 1985).

Second, the culture and traditional beliefs of the many tribes vary significantly. Each tribal group has a unique set of creation stories, religious doctrines and sacred taboos. Each tribal group responded to the world in individual ways, developing their own distinctive view of life and disability. And while many American Indian people have "melted" into the broader society, many still hold to their old ways and traditions. This "living in two worlds" is problematic enough; coping with disability adds a "third world" of difficulties (Ft. Peck Reservation Focus Group, 1996).

The American Indian Disability Legislation Project

The major goals of the American Indian Disability Legislation (AIDL) Project was to develop more understanding of the concept of and reaction to disability among American Indians, and to create a process for tribes to consider their own disability legislation. In addition, the Project wished to garner information that might be used to educate the broader society and its professionals of cultural concerns unique to each tribe. Project staff also sought examples of how the broader culture might learn from the Indian culture that, in some features, has a more accepting and tolerant society. In an effort to accomplish these goals, the Project developed and tested methods for fostering the adoption of disability legislation by American Indian tribes that is consistent with the principles established by the Americans with Disabilities Act, and is respectful of tribal sovereignty and cultural diversity.

General Approach

It is critical in a project addressing issues of importance to American Indians that tribes be involved and in control. Four strategies were followed to insure this. First,

key staff, including both Principal Investigators, were Native Americans. Second, a 13-member Advisory Panel[3], representing 11 major tribes, was involved in all major decisions in the project. Third, the Advisory Panel worked cooperatively with the National Congress of American Indians obtaining their endorsement. Fourth, staff and Advisory Panel members interacted productively with tribal officials nationwide. Finally, staff worked informally with members of the Consortia of Administrators for Native American Rehabilitation (CANAR) to keep them informed[4]. Two CANAR members worked as Project Advisory Panel members.

National Survey of Tribal Governments

The project was divided into two major stages. The first was designed to assess the status of tribal policies and attitudes toward disability. The second was to develop and field test a process for tribes to use in considering their own disability policy and legislation.

The first phase of the AIDL Project focused on developing and conducting a survey of 143 tribal governments, representing over 600,000 people (Fowler, Seekins, Locust, Dwyer, & Duffy, 1995). Researchers assessed the awareness of disability issues and the status of tribal disability policies on the reservations of responding tribes. The Project sent surveys to a total of 685 tribal organizations. Below is a summary of the findings.

Currently, only about 6% of the respondents indicated their tribal governments were very familiar with major disability legislation, including Sections 503 and 504 of the Rehabilitation Act of 1975, IDEA and the ADA. One tribe of the 143 surveyed has reported adopting the ADA. Several others have said that while they have discussed access and employment issues, they do not have written policy. As such, disability legislation among the tribes remains an unaddressed issue of importance.

In 1995, many of the tribal groups knew very little about the disability policies or programs of Indian nations. We based this conclusion on the low rate of return of our mailed surveys. Of 685 surveys mailed, only 112 (less than 18%) were returned from the lower 48 states, and 31 of 224 (13.84%) from Alaska. If there had been more

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[3]The AIDL Advisory Panel was comprised of professionals, paraprofessionals and consumers who brought a broad range of knowledge, experience and expertise to the group. Initially, the Panel met monthly, then quarterly, via teleconferences. They also met at various meetings including NCAI and CANAR.

The AIDL Project staff would like to thank the Advisory Panel members for their insights, contributions and diligence in helping to create this unique model.

[4]Established in 1993, the Consortia of Administrators for Native American Rehabilitation is a professional organization devoted to addressing vocational rehabilitation issues pertinent to Native Americans and Alaska Natives.

knowledge — and thus more policies and programs — we would expect our survey return rate to be greater. And, as stated above, only about 6% of respondents thought their tribal governments were very familiar with major disability legislation.

The rate of disability among American Indians in 1995 was approximately 22.6%. This figure was computed from the total number of tribal members in the sample group, and the total number of people with disabilities in that group, as reported to us on the survey. Cultural or traditional beliefs may influence the way Indian people perceive illness or disability. Some conditions such as arthritis, diabetes and slow-to-learn may not be recognized as disabilities and may have been under-reported.

The sample group data suggests that satisfaction among tribal members with disabilities regarding respect, opportunity and accessibility issues in their communities is 45.4%. Although this satisfaction rate is low, only 9% of the tribes reported any tribal court cases concerning disability issues. The conclusion was that either: a. tribal members did not know how to access legislation in their behalf, or b. there is no recourse, because the tribal governments had no mechanism for protection of people with disabilities.

Schools, stores, churches, Bureau of Indian Affairs buildings, federal buildings, and tribal court and jail facilities were accessible about two-thirds of the time (66.9%). Other major tribal facilities such as health centers, council buildings, community buildings and senior citizen buildings were accessible nearly three-fourths of the time (74.2%).

Across all service categories, the availability of services to people with disabilities had an average of 71% availability for Indian Health Services, tribal health services, special-education services, vocational rehabilitation services and home health-care services. Other services such as senior citizens centers, residential facilities, independent living centers, sheltered workshops, respite services, developmental disabilities services, group homes, adult day care and other programs were reported available an average of 11% among the tribes. While the majority of the most available services were part of the tribal structure, only about 10% of the other services were tribal services. It appears that if a service is part of the tribal structure, members have a much greater chance of accessing it.

Most tribes do not currently recognize the need to provide funds to deal with disability issues. Only 13% of tribes have a line item in their budget for disability issues.

Diabetes (29%), emotional problems (22%) and slow-to-learn (11%) are the major categories of disability among tribal members in the lower 48 states. In Alaska, emotional problems ranked first (31.3%), slow-to-learn was second (17%) deaf or hard of hearing was third (15%), and diabetes was fourth (11.6%). It appears that many of those with disabilities may need more attention than currently given.

In 1994, most tribes did not appear ready to establish disability legislation. However, 110 of 143 of the survey respondents (74%), said they believe their tribal government would be interested in participating as a focus group for establishing disability legislation within their tribe.

It is important to note that the conclusions are based on data from 112 tribes and 31 Alaskan Native villages, and may or may not be applicable to all tribes. However, the process of random selection generally yields representative data. As such, the Project staff feel that the data is fairly representative of tribal governments and people nationally. Our work with the National Congress of American Indians, and directly with many tribes in various parts of the nation, indicate that the concerns, percentages, ages, issues and resolutions of disability legislation stated in our data is a fairly accurate reflection of the national picture among tribes.

Tribal Disability Actualization Process

The second phase of the AIDL Project centered on focus group development and implementation. The original plan was to select five to seven tribes from the survey that indicated interest in participating in the focus group process. Profiles were developed for sample tribes selected. Each profile consisted of: the name of the tribe, its population, cultural group and number of people with disabilities. The profiles were presented to the Advisory Panel for review and a request that 10 tribes be selected for a potential focus group list. Advisory Panel members based their selections on tribal population, number of represented disabilities and cultural/geographic representation (see Map in Appendix B). A list was then drawn of those tribes having the most Advisory Panel selections ranked as first, second, third and so on.

Next, staff began planning implementation of the process by contacting tribal representatives as indicated on the survey. Staff discovered that, during the time the Advisory Panel was reviewing the profiles, several things had occurred. First, the contact people as indicated on the survey had changed. Second, the tribal government itself was in transition or reorganization. Third, some selected tribes no longer chose to participate. In addition, paying for travel to various sites raised the additional criteria of sufficient resources to support these efforts. Eventually, staff contacted five sites, representing 10 tribes, and were invited to present the process.

Procedures

The Tribal Disability Actualization Process model was based on work done by Brown (1986). Its major steps included identifying and developing key leadership contacts, seeking tribal authorization, holding cultural discussions and focus groups, and developing and implementing policy recommendations.

Identifying Key Leadership Contacts

The first step involved identifying and developing a contact within a tribe who was interested and willing to take a lead in advocating for disability issues. These individuals or groups are necessary and become responsible for educating the community, organizing the focus group and hosting the initial disability discussions. They also play a significant role in relationship with the tribal government.

Tribal Authorization

The second step involves seeking tribal governmental authorization. This process often starts by making a presentation to individual government leaders, or to governmental bodies, about the importance of disability issues. Ideally, the tribal government supports the process through official resolutions. This directly involves tribal law-makers in the process and sanctions the focus group as a recognized body.

Focus Groups and Cultural Discussions

In step three, the disability discussion groups or focus groups are constituted. The model uses a two-day workshop format. After a tribe has agreed to participate, Project staff help with logistical arrangements. Two handbooks, developed by AIDL Project staff, helped focus groups develop disability legislation. *How to Hold a Successful Focus Group Meeting* was written as an aide to facilitate the meeting process in a culturally-sensitive manner. The manual begins with a brief discussion of the importance of cultural awareness. An overview of a recommended meeting design, a "talking circle," and the roles of meeting coordinator, facilitator and recorder are next described. A short section gives a few tips on running the actual meeting. And finally, in "Basic Communication" we review conditions for good communication and offer tips on effective listening.

A Guide to Developing Disability Policies on American Indian Reservations was written as a tool to enable the focus groups to seek their own solutions to disability issues. The *Guide* helps the groups begin discussions about their personal and tribal beliefs about disability. It then covers the rights of people with disabilities, current federal disability laws, how Indian tribes have addressed the issues and the results of AIDL's national survey. It also asks the participants to consider what policies might be appropriate for their reservation or tribal land.

A number of handouts were also written to facilitate the process. *Disability Laws* briefly discusses the ADA, Sections 503 and 504 of the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act. *How Have American Indian Tribes Addressed Disability Issues?* outlines a few options recently chosen by tribal governments. And finally, *AIDL Survey Results* and *Ruralfacts: American Indians and Disability* summarize the findings of our national research.

These materials are sent to the tribe's focus group contact person to familiarize them with the process and to facilitate organizing the meeting. Since the model uses a self-directed approach, it is up to the tribe's representative to manage the meeting logistics and to invite key tribal members to participate. AIDL staff attend meetings and are available to answer questions or make suggestions but the onus for a successful focus group is with the tribe.

The first phase of the focus group process (usually the first half-day) centers on disability education and discussion of the group's tribal beliefs, culture and traditions. "Most Indian cultures have a high degree of integration between their religious beliefs and their beliefs about health. Healing cannot be separated from culture, sacred narratives, or religion, nor can the social behaviors of the Indian be separated from these things." (Locust, 1985). To develop disability policy, the group must first assess what is culturally-appropriate for their people.

An important initial step in this process is to review individual and tribal beliefs about disability. In conjunction with this discussion, language that is currently used by non-tribal people in rehabilitation is defined. The group compares and contrasts their beliefs with those of the rehabilitation profession. This helps bridge the gaps between rehabilitation language and tribal people's understanding of disability. It also helps to reduce existing and potential barriers to disability policy development.

As focus group members discuss their cultural beliefs about disability, a "natural" needs assessment occurs. They begin to learn the vernacular of rehabilitation that leads to the discovery that there are unmet needs that may have traditionally not been considered. The second phase of the model helps the participants construct a viable, cohesive group to ensure continuity of the process. Project staff provide leadership, systems-change and advocacy training and continuing education on disability issues.

The focus group process may also include existing state and local disability service providers. After permission is granted from the focus group Coordinator, as a representative of the tribe, providers are invited to present their programs to the focus group. Service providers such as the Tech Act projects, local independent living centers and other state agencies have participated in the meetings. These agencies have presented information to the respective tribes about their services and how they may help the tribes address their unique disability issues.

With guidance from the AIDL Project staff, current tribal administrative policies are reviewed for any blatant omissions or instances of discrimination. Suggestions for revisions to tribal law and policy are then developed. The group also begins to draft new policies designed to protect the rights of Indian people with disabilities living on their reservation addressing accessibility, employment, transportation and housing.

The focus group process helps tribes recognize important aspects of disability policy development that may not be evident at first glance. Issues such as implementation and enforcement of disability legislation, and questions of jurisdiction and sovereignty rights are of prime concern to tribal people. These matters are discussed and approaches for dealing with them are developed, examined and understood by each tribe individually. The AIDL model promotes self-directed adoption of disability legislation that is culturally and socially relevant for each tribe.

Policy Development, Recommendations and Impact

In the fourth phase of the process, each group then recommends to their tribal councils various approaches to disability legislation. These include: to adopt the Americans with Disabilities Act directly, change the existing Law to meet the needs of the individual tribe, create unique tribal legislation or not to adopt disability laws.

Results

Disability actualization groups were initiated on five reservations, representing tribes from three cultural/geographical regions. Table 1 lists each group, tribes represented and the population of the reservation. A brief case history of each site is presented.

Table 1
Participating Tribes and their Populations

RESERVATION	TRIBES REPRESENTED	POPULATION
Flathead	Salish Kootenai Pend d'Oreilles Kalispell	6,000*
Fort Peck	Assiniboine Sioux	6,800
Pine Ridge	Oglala Sioux	23,000
Nez Perce	Nez Perce	1,500
Navajo	Navajo	200,000

*Approximately 22,000 non-Indian people also live on the Flathead Reservation.

Flathead Reservation

The Flathead Indian Reservation, established in 1855, is home to the Confederated Salish and Kootenai tribes. The tribes are a combination of the Salish, the Kalispell, the Pend d'Oreilles and the Kootenai. All are Plateau Indians and share similar culture. The Reservation's total population is about 22,000, with approximately 6,900 enrolled members of the tribes. Four thousand tribal members live on the reservation and 82% of the reservation population are non-Indian. (Tribal Enrollment, 1996).

The reservation lies in the Mission and Jocko Valleys of northwestern Montana, bordered on the east by the Mission Mountains and to the south and west by the Coeur d'Alene and Cabinet Mountains. It comprises over 1.2 million acres, most of which is tribally-owned (57%). The remainder is deeded to non-Indians as a result of homesteading in the early part of this century (Davis, et.al., 1994) resulting in an "open reservation."

In 1934 the tribes were chartered under the Indian Reorganization Act (IRA). They have a constitutional government similar to the United States. The tribal government consists of 10 council members elected from the general population of enrolled tribal members. The reservation is split into districts that are based in the major tribal concentration areas of the reservation. There are five districts with two council members elected from each district. Candidates can only run in the district that they reside in. This allows for an even distribution of members of the council from different tribes.

Initial Contact and Tribal Authorization

Contact with the Flathead Reservation was initially made through personal contact by two AIDL staff members. The project was discussed with the tribal Vice-chairperson who gave tacit agreement to participate in the focus group process. The Section 130 Project Director was approached and a Vocational Rehabilitation (VR) staff member was assigned to help coordinate a focus group. The information was then presented to the Tribal Council. To facilitate the process, the Tribal Council was asked to allow a change of duty station for employees that wished to attend the meetings. This was approved and employees were encouraged to attend if their other duties allowed.

The VR staff member arranged and coordinated the meeting, including selecting whom to notify to participate and when to schedule the meeting.

Focus Group

The first meeting, held in the middle of October 1995, was attended by several key people from within the tribal government structure. Representatives from tribal vocational rehabilitation, facilities' management, education, tribal health, the housing authority, the People's Center and the tribal council were present.

Cultural and Personal Beliefs. The focus group began with discussions of the participant's personal and tribal views and experiences about disability. While talking about beliefs of the Flathead tribe about disability, many ideas were discussed. As with all groups, there are differences of opinion and beliefs. (See Table 1). It is also important to remember that these issues affect not only our generation, but the generations before us and the generations to follow. We need to provide a safe and productive environment for our children and our elders.

There seems to be a difference in the attitudes of individuals from different age groups. Elders' perceptions of what a disability is, and younger more-proactive generations' perceptions, are very different. Often elders feel that a disability is just the way that life is supposed to be. This may result in them failing to recognize that they need, and can receive, services and accommodations. This may limit the role they take in everyday life and the functioning of the tribe. It also means that the tribe loses valuable members though they are still living. Younger people, on the other hand, may be more inclined to ask for help. We need to help elders and people with disabilities become active and valued members of the tribe

The very young are often ignored until problems become so severe that they fail in school, drop out or are in trouble with the law. Often the first person to discover a learning disability is the child's parole officer.

The group agreed that often a person with a disability does not ask for services or needed access because of the stigma of being labeled "disabled." This seems to be most prevalent with veterans and older people who may think that there is nothing wrong and that this is the way it is supposed to happen. As people get older they expect that they will be unable to do things that they have done before and therefore do not consider age-related problems as disabilities.

Service providers need to be aware that often a label will prevent a person from requesting services or even seeking basic help. If a label prevents a person from requesting services or accommodations then the label needs to be removed. Service providers also need to learn to network with each other to ensure that person's needs are met. Often people want to be able to come to just one office, get all of the services they need, or at least find out what is available elsewhere.

Table 2

Synopsis of Views Expressed and Issues Discussed

- We don't see people with disabilities at tribal functions, is it because they can't get there?
- Elders need to be involved in any process that changes values and beliefs.
- Persons with disabilities should be treated with respect.
- Persons with disabilities should be allowed to do what they can do without barriers being put in their way.
- The Reservation does not have what people need, so they move away from home and family. This is not right.
- Disability "does not exist!" It's an uncomfortable issue, therefore it is not discussed.
- Everyone has some type of disability, we just don't admit it. Even glasses or medication can be considered assistive devices.
- The tribe has tried to make access changes, but may need technical assistance in the future to provide better services.
- There is a need for advocates to help people who have disabilities and training to teach people how to ask for what they need.
- Change will not happen overnight.
- We need to educate 'normal' people about people with disabilities and what they can, and cannot do."
- How do you foster awareness about disability and what types of educational tools can you use to do this?
- Reservations differ greatly in their treatment of people with disabilities. The Flathead Reservation could become leaders in the treatment of persons with disabilities.

Finally, the group agreed that the Flathead Reservation is a liberal and progressive reservation and that they should be proud of the strides that have been made.

After discussing these basic issues, the group began to address functional issues such as those addressed in the ADA and Section 504 of the Rehabilitation Act, including employment, access and transportation.

Public Accommodations and Access. The idea of personal independence was discussed as very important for individuals with disabilities. This means that people with disabilities should have access to the same services in the same manner as people without disabilities. People with disabilities should be able to participate in activities and programs with the same ease as everyone else.

Access is a universal problem. The ability to go and do what you want, when you want to do it, is a basic right that most people take for granted. The person with a disability, however, is often restricted by their physical environment and the conditions in which they live.

The tribe has been trying to upgrade and make more services and buildings accessible for people with disabilities. These efforts are like a patchwork and there are gaps that still need to be filled. The lack of funding is a real barrier to service providers and businesses becoming accessible. Though the tribe currently does not have a code in place, attempts to make needed changes to provide access to all buildings and services are being made.

The biggest factor preventing access is the lack of funding. Lack of money, to do necessary and sometimes costly renovations, often prevents people from even trying to make things better. As the Tribe has become aware of the need to provide services and access to all tribal members, they have tried different methods often with mixed results.

An example of a recent problem was the placement of a ramp in front of the Tribal Complex building. In an effort to make the Complex building more accessible, the Tribal Council authorized a temporary "fix" by building a non-compliance ramp. A cement ramp was poured. Unfortunately the ramp's grade was at least 15%, it measured three feet in length and was only 30 inches wide. The result was a dangerous situation.

As with the discussion about beliefs, an important and frequently discussed issue was the need for disability education and technical assistance. There is a need for training to help people with disabilities to become more active in asking for things that they need and want. One comment was that consumers themselves need to push for services and accommodations. When they don't, the need remains "invisible" and does not get met.

Access issues that pertain to making the PowWow grounds more accessible for persons with disabilities were discussed. Some suggestions were: wheelchair accessible bathrooms need to be installed and signs that explain where they are located need to be highly visible; the designated parking areas was a good idea, but the surface is often impossible for a person with a wheelchair to negotiate on their own; a paved pathway encircling the dance arena and booth areas would make it easier for elders, people with disabilities and parents with children (baby-strollers) to move around; and designated areas for elders and wheelchair-users at dance areas.

One individual commented that the Tribe and area businesses put in "temporary fixes" that become permanent. Temporary fixes may even be dangerous. They are often poorly constructed and do not follow known codes. Solutions should be made

to the highest possible standards and should be designed to last as long as the program or building is in place.

One area seen as needing immediate attention is the lack of signage. This is a low cost accommodation that can be used with existing facilities and would ensure that the public is aware of the accommodation. An example would be to post a sign saying the electric door is at the far south entrance to the BIA Tribal Complex Building.

Service providers need to devise a way to track: the types and actual numbers of people with disabilities, the services they receive and the services they continue to need.

Employment. Participants estimated that there is approximately a 60% unemployment rate among tribal members on the Flathead Reservation. There were no figures or even guesses on the rate of unemployment of persons with disabilities on the Reservation. However the feeling was that the estimate would be high.

The key to providing employment for people with disabilities is education. We need to educate the people with disabilities, the people who provide services and the people who provide jobs.

Tribal personnel polices were then reviewed. Personnel Policy Ordinance 69B, Chapter 13, Section 3 stated,

> "An employee may be terminated for disability when he cannot perform the required duties because of physical or mental impairment. Department Heads are strongly advised to work with the Personnel Director regarding all cases of termination for mental or physical reasons to insure that **proper medical evidence** substantiates the termination." (See Appendix C).

The group decided, with agreement from Tribe's Vice-Chair, a proactive statement about hiring and retaining people with disabilities as employees was in order.

Next, the group discussed an informal policy used by Tribal Health to access the Social Security system for youths with disabilities who are 16 years of age. This provides the youth with a minimal income and saves Tribal Health monies. The practice, however, has been a deterrent to getting young people employed, because they then may lose their Social Security Insurance (SSI) benefits. Some individuals have dropped out of the tribal Vocational Rehabilitation (VR) Program for fear of losing their insurance and monthly checks.

There are few formal written policies that deal with disabilities but, some relevant informal policies are followed by the Tribe. For example: Leave sharing is used by

most departments of the tribal system. This allows people to donate their accumulated sick leave to a fellow worker if their funds have been exhausted due to prolonged illness. Further, administrative leave is often granted for long-term illnesses or other reasons when a long-term absence occurs. Hardship leave can also be arranged for reasons that are not covered by other leave arrangements.

Insurance policy requirements can be a detriment to employment of persons with disabilities. Not only are policies for pre-existing conditions usually more costly, they may be impossible to find. Often a person will refuse to go back to work for fear of losing their SSI or disability benefits. They may stay with a job that is not suited to their talents or needs just to keep an insurance policy intact.

Tribal application forms and job descriptions need to be looked at for discriminating language. For example: the statement, "A Montana driver's license is required" is on most job announcements may screen out individuals who do not have a driver's license even if driving is not a job requirement.

Transportation. Currently, when handicap parking is available, it is not enforced by a tribal agency. Who should be responsible for enforcement and how can they be recruited?

Transportation, especially on the Reservation, is limited for people with disabilities. If you do not have a vehicle or know someone who does, you may not get to your destination. The Rimrock Trailways bus (an interstate transporter) makes one round trip per day through the Reservation. There is cab service in the city of Polson and the elders have a van but it is not wheelchair- accessible. The Lake County Senior Citizens have a van that runs a posted schedule that changes monthly. There is a private transportation service called Mission Valley MediCab. There is also a non-profit service that can be used to travel to and from non-emergency medical services. This leaves gaps in the transportation services that are available on the Reservation.

Currently, a transportation system called Transportation Resources for Independent People (TRIP) is being managed by the Salish Kootenai College (SKC). It is a three-year grant to provide transportation to and from any employment-related appointment or to and from work. It is a fee-based system with a sliding scale. Tribal VR often initially subsidizes the service for an individual and as the person becomes more independent, they then assume the costs. The user must have a disability and the travel must be employment related.

The program purchased several vans and two buses that are wheelchair-accessible. The service transports seven individuals to their jobs daily and operates a regular schedule of 13 trips weekly for people going to job-training and medical appointments. The average use per month has been about 6500 user-miles. The grant ends in September 1996 and currently there is no plan to continue

the service beyond that date. It was asked, "What is the tribe's role and responsibility when the grant ends?" And "What are the present TRIP grant personnel doing to ensure continued services?"

As with previously discussed issues, education is the key to providing transportation services to individuals with disabilities. The non-accessible van for the elders is evidence of this need.

Open Reservation Considerations. The Flathead Reservation is an "open reservation." This means that reservation land was opened to purchase by non-tribal people. Which brings the question of jurisdiction over services on the reservation up for discussion. Jurisdictional issues must be addressed when applied to tribal government, businesses owned by tribal members and businesses that are jointly owned by a tribal member and a non-tribal member. Currently disability rights protection for people with disabilities does not exist on most of the Reservation. Table 3 lists the issues discussed but it was clear that developing answers would take time and commitment.

Table 3
Open Reservation Considerations

- The Flathead Reservation is unique place and has unique concerns due to its open Reservation policy and the complicated logistics that exist here.
- Issues dealing with joint ownership of businesses.
- The need to make resolutions to the Tribal Council Reservation-wide and how this might be accomplished.
- Who will enforce these resolutions and who will have jurisdiction.
- Access issues would be complicated if there are separate codes for tribal and non-tribal entities.
- Transportation: Who is responsible for providing or maintaining transportation? How can it be done?
- Employment
- Is there a need for a tribal enforcement-compliance officer to oversee disability concerns?
- Funding for disability awareness education, adaptive equipment, technical assistance and the like.
- Gambling monies were also discussed as a possible funding source but the current impasse between the Tribe and the State of Montana may preclude consideration of gaming as a source of funding.

Public Awareness and Education. The issue of education was discussed throughout the two days. Here are some problems and solutions that were discussed.

It was decided that a long-term ongoing process of education of all age levels is needed, beginning with the Tribal Council. There were various suggestions of ways to accomplish this task.

The group felt that it was important to develop a long-term plan for education and awareness building. Some strategies that were discussed included: Awareness programs in the school systems on the Reservation, Awareness Days at tribal offices that include Tribal Council members, articles in local papers about disability issues and recognition for businesses and tribal departments that are doing a good job of making accommodations and accessibility a part of their everyday operation.

The creation of a Coordinator of Disability Services was seen as a possible solution to the problem of education, accessing services and to help make the Reservation more access-friendly.

Policy Development, Recommendations and Impact

A disability policy group was formed as the final accomplishment of the first meeting. The group used *A Guide to Developing Disability Policies on American Indian Reservations*' section entitled, "Your Tribe and Disability Legislation" as a tool to address the issues and consider solutions.

The group was named the Total Access Committee. Officers were elected and the group held their first formal meeting. During the meeting, they nominated other key individuals to participate in the group. They also discussed ways for recruiting members and how to start the education process.

The following are a few strategies for recruiting members for the policy group: Several members of the current committee will attend elders' meetings and ask for volunteers who would like to participate; attend the luncheons at the regional senior citizens' centers for the same purpose; and Council members will be contacted and asked to participate.

The first issue the group decided to address was the immediate problem of the ramp in front of the Tribal Complex building. The Tribal Council was approached after two tribal members (a person in a wheelchair and a person who uses a scooter) were injured while attempting to use the ramp. Advocates representing the local Section 130 Project and the AIDL project presented the problem and offered suggestions to make the ramp a safe accommodation. Two days later, the temporary

"fix" ramp became a 20-foot wide access area, closer to code in grade, with designated accessible parking areas.

In addition to taking immediate action on the ramp, the Council has appointed and provided training for a designated crew to build or repair ramps on the Reservation. The Tribal Council also asked the group to recommend additional policies and procedures to address accessibility standards of all aspects of the Housing Code for the Housing Authority. These recommendations have been made and are being integrated into practice.

Second, the group decided to address personnel policy issues with assistance from the Tribal Council Vice-Chair. The group developed the following statement and the Vice-Chair agreed to have it placed on the Council's agenda.

> "A. The Confederated Salish and Kootenai Tribes prohibits employment discrimination against 'qualified individuals with disabilities.' A qualified individual with a disability is: an individual with a disability who meets the skill, experience, education, and other job-related qualifications of a position held, and who with reasonable accommodation, can perform the essential functions of a job. B. A person with a 'disability' is an individual who: - has a physical or mental impairment that substantially limits one or more of his/her major life activities; - has a record of such and impairment; or is regarded as having such and impairment."

The Tribal Council amended their personnel policies as suggested by the group (see Appendix C).

Third, the group developed recommendations that have been instrumental in the creation and passage of a resolution adopting the spirit of the ADA. It also states, "...that the Tribal Council of the Confederated Salish and Kootenai Tribes shall direct ... any Tribal department whose involvement will be necessary to address and meet the guidelines of the ADA and to participate in said Committee (Total Access Committee) to ensure compliance." (see Appendix C).

Focus group members meet on a monthly basis. AIDL staff have attended many meetings and have provided training and technical assistance about the ADA, the Americans with Disabilities Architectural Guidelines (ADAAG), and basic group development.

Navajo Reservation

More than 200,000 Navajo people make up the nation's largest reservation-based Indian tribe. They speak an Apachean dialect belonging to the Athapaskan language.

The Navajo Reservation, established in 1868, is largely located in the northeast corner of Arizona on the Colorado Plateau. It also extends into the southeast corner of Utah, the southwest corner of Colorado and the northwest corner of New Mexico. Over 28,800 square miles make up the largest reservation in North America.

The Navajos rejected the IRA in 1935. The Tribal Council then appointed a constitutional assembly and wrote a new constitution that was ultimately rejected by the Secretary of the Interior. After many years of political struggle and social and economic maneuvering, the Tribe eventually gained control of their lands through legislation of regulations that guarantee tribal autonomy. Finally, in 1990, the Tribal Council instituted a government with three branches: the executive, the legislative and the judicial.

The reservation is divided into five agencies. They are located in Tuba City, Chinle, Fort Defiance, Shiprock and Eastern Navajo. There are also twenty-three land management districts. Each district has a proportionate number of Tribal Council delegates according to its population. The local community or "chapter" is the smallest political unit; an election district is made up of two or more chapters. There are 109 chapters and 37 districts.

Initial Contact and Tribal Authorization

Contact was made with the group from the Navajo Reservation in a coordinated manner. First the Native American Research and Training Center at the University of Arizona suggested working with a group of individuals that they were training in leadership development. A second contact came through an AIDL Advisory Board member who was a part of the training group. He coordinated the focus group meeting.

Focus Group

Two major issues were discussed at the first meeting of the Navajo group. In 1979 the Tribe passed an affirmative action law that has never been actively enforced. AIDL assisted the group to obtain copies of the legislation in an effort to make more people aware of it and try to attempt to make it work better. The need for tribally-based independent living services was also discussed.

Beliefs - Traditional and Tribal. Discussion on the first day focused on the beliefs about disability held by members of the Navajo Tribe. Some of the individuals

were more open about their beliefs than were others. A member of the Hopi tribe was also present and was able to include information about differences in the beliefs of both tribes.

The members of the group believe there is a change of beliefs occurring. This change is toward a more "Anglo" way of thinking. Boarding schools have influenced this change. The Navajo Tribe is in the process of phasing out boarding schools. Most children are now going to public schools provided by the state. However, there are still a few boarding schools operating around Tuba City and Kayenta.

A second cause of the shift in beliefs is that when injuries occur, more people with severe disabilities live because of advancements in medical technology. Often an injury means that traditional beliefs must be modified to allow personal care and exposure of one's body to others. "The family spoke one way before the family member was paralyzed, but then things started to change."

Another observation is that some tribal people may have a fear of authority. This may come from the above mentioned "Anglo" influence or from the treatment that tribes have historically received from the federal government.

The group felt that tribal beliefs are being lost. Children don't know simple things. All the participants felt the Tribe needs to address this issue in some manner soon.

Many Navajo are traditional and still practice their religion. The Navajo believe that the snake can cause illness and even death. Snakes may cause paralysis or sores where they touch a person. The snake is believed to be unclean. Navajo's cannot wear anything made from the skin of the snake. Snake skin purses, belts and other articles are also forbidden. The Navajo do not wear deerskin except during religious ceremonies. When deerskin is worn it is believed that the person will become like a deer — scattered and running from thing-to-thing in their mental state.

By contrast, the Hopi, also a traditional people, believe the snake to be a very sacred being. The Hopi dance with the snake and revere them. And the Hopi do not have restrictions against using the snake for clothing.

Intermarriage among Navajo and Hopi people is becoming more common, since the Hopi Reservation is located within the Navajo Reservation. These variations in beliefs can cause conflict within families when one member is Navajo and the other is Hopi. Other areas of family life may be affected as well.

Some people believe that you can cause accidents to happen by your actions. And that others can influence what happens to you; they may even be the cause of an accident that leads to a disability. It is also believed that if you play around with things that you should not (like playing with crutches or wheelchairs) you could cause

yourself to become a wheelchair-user or to use crutches later in life. This belief makes it difficult to provide disability awareness training that asks a person to "take on" a disability for a period of time.

Beliefs about the dead make it very difficult for Navajo individuals to become doctors, EMTs or work in hospitals where they may have to touch a person who has died. One person talked about a relative who was studying to become a doctor. Because of the conflict between his traditional beliefs and the requirements of his study he must perform cleansing ceremonies each summer to prevent harm from happening to him.

Another individual related his experiences as an EMT and how difficult it was to attend to the needs of someone who is severely injured or might be dead. He talked about the conflicts he felt when he encountered a traumatic situation; knowing that he needed to do his job, yet realizing that his actions may affect him later. He also wondered if helping the injured person would change the course of that person's life. He wondered if it was right for him to do this.

These examples illustrate the notion of "living in two worlds" and how beliefs about disability issues may be viewed or accepted. An important question for members of the group is, "Has medical technology altered the lives of the Navajo in ways that are not spiritually healthy"?

The concept of "living in two worlds" was discussed further. The members of the group were very aware that their two worlds are not always compatible. The need for assistive technology or devices is obvious but this type of help often interferes with traditional views. Many times a person who needs a device will refuse it because they have no way of reconciling the aid with their religious or traditional belief about the self.

The Navajo world is compounded by trying to maintain traditional values, live in a modern society and receive medical treatment which might interfere with traditional convictions. The introduction of foreign objects into a person's body can impact the spirit in negative ways. Therefore a traditional person will often not have needed medical treatment if it involves "invading" the body because they are unwilling to chance the spiritual consequences they feel might occur. This may lead to severe complications for individual and their family that may be considered unnecessary in the eyes of "modern" health care providers.

Traditional beliefs about the body create problems in other areas of health care. A service provider who is unaware of a person's beliefs about their body it can cause difficulties. What is seen as superstition by some is a way of life for many traditional Native American people. Lack of respect for another's belief can cause problems for both the individual in need of care and the people trying to provide the care.

One example is early medical care for pregnant women. Often the only available medical care provider is a male. Traditional belief prohibits any man, other than the woman's husband, from seeing her without clothes. A traditional woman may have her baby at home without "modern" medicine. This may be seen as neglectful or abusive disregard for the woman's health and the health of the infant by the medical profession, when it is what the woman feels necessary to protect their spiritual well being.

There are many taboos and beliefs about childbirth and what a woman needs to do and how it can affect the unborn child. A mother may be blamed for her child's birth defects if she has done something taboo while she is carrying her child. Birth defects may also be blamed on someone who wishes harm to come to the family. Traditional and modern medicine look at birth defects, and disability in general, very differently.

For some people there does not seem to be a way to bridge the gap between modern medicine and traditional beliefs. Traditional Navajo ways must be maintained to ensure spiritual wellness. There is often no way to include medically necessary procedures in the traditional way of life. This creates difficult problems for people with disabilities as well as their families. They often have to choose between their traditional values and their health. Many people must leave the reservation to receive services; losing contact with their families and support systems. They may also lose the ability to maintain their spiritual wellness and lose touch with their religion and the benefits that it affords.

Children are sacred and much-prized for Indian people. A person needs to have children to fulfill their role in life. When a person is injured, especially with a spinal cord injury, there are questions about if they can have children. And if they do have children, how can they care for them.

There is also a taboo about discussing sexual matters. Individuals with disabilities need answers to questions about sexuality and how it relates to their disability. Specific questions were asked about whether people with disabilities can have children and, if so, how. People also shared the information they received from their rehabilitation experiences and from other sources. Several people were told that men who are quadriplegic would need a surgical procedure to harvest sperm for artificial insemination to have children. They were also told that the cost was great and IHS would probably not cover the procedures. AIDL will research this issue and pass the information to the group.

Each individual is different and each person should seek the advice of a specialist in this area before giving up on the idea of having children. Medical science makes rapid advances and what was true last year may no longer be the case this year.

Levels of disability or what is sometimes called the "hierarchy of disability" was discussed. One person stated that another's disability was "lucky" because they could have children. The discussion continued from several perspectives of each individual, sharing what people with different types of disability encountered in their activities of daily living.

One way that individuals sometimes deal with this issue is to choose partners who already have children and help to raise them as their own. Another approach is to adopt children. This is difficult, however, because adoption agencies will often refuse to place a child with a parent with a disability. The adoption agency may believe that the person with a disability is not capable of being a good parent. This situation does not occur as often as it use to, but it still happens.

As science advances the options for persons with disabilities are expanding. Medical advances are providing better chances for people with disabilities of all types to become parents. Technology is also making it easier to provide the care that children need. Assistive devices are being developed for parents with mobility impairments to more easily care for infants and small children.

Personal Care Issues. The discussion about beliefs carried over into the provision of personal assistive services for people with disabilities. Due to the traditional beliefs about self, it is often taboo for members of a person's own family to speak to each other much less do personal care tasks for that individual. This was seen as a real problem by the more traditional members of the group.

One individual talked about these taboos in more detail. There is a cultural belief that says that an adult male may not let his mother, sisters, sisters-in-law or nieces see him naked. This belief clashes with the medical model of rehabilitation that states, to the individual and the family, that they have little choice. Due to the level of care required for some individuals and the need for family members to assist with care at times, these beliefs cannot be considered, especially in the case of a life threatening emergency.

What to do in the case of a life threatening emergency was discussed at length. Members of the group decided that they would all ask certain members of their families to do things for them, even if it was taboo and very embarrassing. They agreed that they would even ask a stranger to help them in this case. One member stated, "I want to live."

The lack of personal care givers in the area compounds the dilemma. A personal care giver attending the meeting stated that he cares for as many as six or seven people every day. He often travels with one of them and must leave the other individuals without assistance for long periods of time. This forces people to rely on

family members who may or may not be trained. It also forces the person to become more dependent on others and lose independence.

Another issue of concern in the discussion of personal care is that often a person will stay in difficult relationship with a significant other because that person provides personal care that may not be otherwise available. One participant stated that he had not had to think about personal care issues, until he broke up with his girlfriend. Now he must ask someone else to do things for him. He said that "it is scary out there on your own." Another person's spouse has continued to provide personal care and live in the same house even though they are divorced. The question was asked, "How many people with disabilities live in difficult relationships because of this?" The conclusion by the group was that there are probably many but it is seen as necessity.

One person had a lot to say about personal care attendant (PCA) or personal attendant services (PAS) issues:

> "PAS is a big worry all the time. I sit and think about these things, wondering what will happen. My parents and I talk about it. They are up there in years and at some point won't be able to continue to help me. It scares me. What will I do? What will happen to me? A rest home? That, I don't want to happen. I can't rely on my other family members (like cousins) because they want money to care for me. So I go to service providers and ask for help with this, but they say, 'I can't pay for family members to care for you because they're supposed to help you for free — they're your family.' Community Health Nurses (CHNs) don't come around, even though they should be. When my PCA does come around, I only get four hours per day and it isn't enough. Sometimes the PCA doesn't show up for days. But if I tell, (the PCAs supervisor) maybe he'll get in trouble and then he will be mad at me. It's hard.
>
> "When we told the rehabilitation staff that my mother and my sisters and sisters-in-law could not care for me because of our tribal beliefs, they told us we had no choice. So mother, sisters, sisters-in-law and nieces are also trained at rehabilitation facility to care for the injured individual. This becomes awkward, especially with the sisters-in-law. The individual with the disability doesn't know what they are thinking. Everyone is embarrassed. No one can talk about it. But someday they (the sisters-in-law, sisters and nieces) are the only ones there to help. It seems like it would be better if a stranger took care of me.
>
> "It was easier in the beginning. My older sister said no big deal, I took care of you when you were small. She helped me a lot the first year. She has moved away. Then I had a girlfriend. She did all of the things that I need help from others with now. She was around for a long time. Now she is not here and I have to ask others to do the things that she did for me with out my asking.

"Lately, my nephews' girlfriends have been taking care of me. At this time they are only getting water for me and making sure that I don't fall off my wheelchair. It is uncomfortable for all of us. We are all embarrassed.

"The care seems to come in levels. The first level is that they (caregiver) only help with getting water, emptying leg bag, picking up things, etc. They rely on the PCA to do the other care. But some days, the PCA doesn't show, and then they have to help my mom or my dad to get me up, shower, toilet, dress and ready for the day. The next level is that they may be the only one around and end up having to learn to do what the PCA does plus what they did before (get water, etc.). Everybody gets burned out."

When asked if he ever considered moving away to get better services, he said, "Sometimes. But I don't have money to move and then I worry about who will help me out there? Will it be the same, like it is here? Too may choices, sometimes I sit and think about what I should do."

Dealing with Disability. When asked about acceptance of their disabilities one person commented, "I don't accept the disability, I deal with it every day." Another individual talked about the need to learn a new way of living. Good or bad you cannot go back to the way it was before. You have to get on with your life and do the best that you can with what you have.

Dealing with a disability is complicated by the tribal belief that was expressed by the members of the group. "People don't see people with disabilities — therefore they don't exist — therefore they don't need services." This is a common belief, especially if disability issues have not affected you or your family. This belief is held by the tribal government structure as well as by the people in general. It causes a lack of available services for people who need them. Another theory expressed was that the government believes that people with disabilities do not vote, so why should we care about their issues and concerns.

These attitudes cause gaps and delays in services that the tribe and health care professionals provide. The gaps and delays may cause people to give up and quit asking for services. Some people become depressed; chose not to live anymore and find ways to end their lives. Alcohol seems to be one of the ways that people cope with their depression and frustration. Others leave the reservation and their families to seek needed care and services.

Many people get negative answers to their questions. If they do not get a negative answer, they are told that they have to wait for the requested service or piece of equipment. The wait is getting longer and longer.

As an example, one person wished to replace a broken shower chair. The individual called his service provider and was told that they would have to fill out the

paperwork to request this new piece of equipment. He would then have to wait until the Arizona Long-Term Care (ALTeC) Board reviewed the request to see if it fit within their management plan. The process could take up to three weeks. If the request was approved, the chair would then be ordered with another two to four months for delivery. In the mean time, the person could not take a shower, or perform other functions in the bathroom.

An informal needs assessment was conducted. The following are the findings from this effort.

What's Here

Arizona Long Term Care (ALTeC): A private company that contracts with the Tribe to provide personal care, medical supplies and other services that can be handled by a case manager. Case Manager: When you sign up for services you are assigned a case manager.

CHN: Community health nurse who works out of the chapter houses. There are 110 on the Reservation, nine in the area around Tuba City.

Independent Living Program: Located in the Windowrock — Shiprock area. Sponsored by the VR with one case manager in the area.

Section 130 Vocational Rehabilitation: Located in Windowrock. Kayenta, Chinle and Tuba City have a representative who comes to the each area monthly.

State VR: Provides services on Reservation but does not have a representative in the area, consumers must to go to them.

What's Needed

ALTeC: Improved access for individuals, more personal care assistants, more training for individuals and PCAs on expectations, roles, etc. More hours allotted for each person, more education about the program at sign up, fewer delays for equipment and supplies, need to provide information about other services available from company.

Education: General education on available services and technology. Individuals need disability awareness training to help us ask the right questions about services. Specific disability information for family members to help them better understand and assist the individual with a disability. Educate communities about barriers that exist (architectural and attitudinal) in order to help solve the problems.

VR and IL services: What's the difference? Who is eligible? Who do I call to find out more about them? What do I have to do? What can they do for me? Why should I talk to them? Who else can help me?

What's Needed (Cont.)

Advocacy Training: Culturally-relevant advocacy training that looks at needs and customs of tribal members. Training should be developed and delivered in native languages.

Traditional Healing: IL and VR programs will not pay for, or use the services of traditional healers.

Culturally Appropriate Services: All services to tribal members with disabilities should be delivered in a culturally-appropriate manneAgencies that work with tribal members should be trained in cultural awareness.

The group discussed a Navajo tribal resolution on disability that was written in 1979. Some people reported that they had heard about it but no one in the group had ever seen a copy of it or knew exactly what it said. One individual stated that he thought it said something about equal access for people with disabilities but he wasn't sure. Other members thought it would be important to get a copy of that resolution.

Independent living services are available in the eastern part of Navajo Nation near Window Rock. Most group participants were not familiar with, or had difficulty accessing these services due to the great distances that must be traveled.

Some specific items that could be addressed by the development of an ILC are:

A fund to provide immediate payment for supplies and equipment could be established. A loan or lease program could also be set up to provide needed equipment on a short-term basis. Training on the use of appropriate supplies and equipment could also be included.

A loan/lease program may be developed using several sources to provide the equipment and funding. Some possible sources are nursing homes, hospitals, the Government Surplus Administration, and people who have used equipment they no longer use. This type of loan/lease program could be used by consumers to try out equipment before they buy. This approach will allow better use of the limited resources most people have.

People should be allowed to attend trainings without being required to participate in other aspects of the program. Trainings should be culturally-appropriate and free to all who might need or want them. This could be accomplished by developing a fund for stipends that would pay the participant in advance of the training.

Service agencies need to realize that a person with a disability is an expert about their disability and may offer excellent help during trainings and workshops for others. They can be presenters, paid by honorarium, or have their expenses pre-paid so they can disseminate their expertise.

The nuts and bolts of developing and running an independent living center were discussed.

Policy Development, Recommendations and Impact

AIDL staff, with additional help from the Native American Research and Training Center at the University of Arizona in Tucson, helped the group develop a proposal to fund a four-state independent living center to serve seven to nine tribes. The group contacted and met with Utah Senator Oren Hatch's staff to discuss supporting tribally-based independent living services.

As a result of this initial meeting with Senator Hatch's staff, the group recognized the need for a broader base of support on the Reservation. They have opened an office and are currently working on group-building strategies. They will again take up the independent living services project in the future.

The group has initiated steps toward arranging culturally-appropriate PAS training for tribal members. They have formally contacted the Tribe for approval and the ALTeC contractors have agreed to participate. However, negotiations have not been finalized as of this writing.

Pine Ridge Reservation

The Pine Ridge Reservation, established in 1887, is home to approximately 23,000 Oglala or Lakota Sioux people. They are considered classic Plains Indians. Originally, the Lakota were one of seven nations that spoke dialects of the same Siouan language. They were known as the Tetons. Later the Tetons subdivided again into seven tribes. The people of the Pine Ridge Reservation are one of those seven, the Oglala or "They Scatter Their Own." (Davis, et. al., 1994).

Located in the southwest corner of South Dakota, the Pine Ridge Reservation is the largest Lakota Reservation covering 1.2 million acres of Shannon, Jackson and Bennet counties. Only the Navajo Reservation is larger in land mass.

Originally, the Tribes of the Sioux people were organized as bands, with a chief or head man as leader. The Lakota people then adopted the IRA in 1934. A Tribal Council with an elected board and district representatives is the current governing system. Today, the new structure and the traditional system, at times, conflict when custom prescribes that tradition be respected and given priority over the Tribal Council's agenda.

Initial Contact and Tribal Authorization

The project's Director made initial contact with members of the Quad Squad[5] at a national Native American rehabilitation meeting in Albuquerque, New Mexico in April 1995.

Since the Pine Ridge Reservation's Tribal Council had passed the ADA as written (see Appendix D), the Tribe soon recognized that although they had approved the resolution, they lacked a process to educate people about disability and implement the resolution.

Quad Squad members shared concerns about jurisdiction, implementation and enforcement issues with the project's Director. First, questions of jurisdiction arose. Would adopting a set of Federal laws undermine the Tribe's sovereignty? Second, who, the Tribe or the Federal government, is responsible for enforcement of the ADA resolution? And third, most tribal members lacked the technical training or expertise needed to implement the resolution. These informal discussions, and continuing telephone communications during May and June, led to an invitation for a presentation of the AIDL model. This accomplished with the aid of a member of the Quad Squad, with Tribal Council approval.

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[5]The Quad Squad, organized in 1989, is a non-profit Oglala Sioux advocacy group. Their mission is to develop and maintain a supportive network to help people with disabilities improve their lives.

An initial meeting was held in July 1995. Its purpose was to acquaint Quad Squad members and other people interested in coordinating the focus group with AIDL staff and to briefly explain the AIDL process. This meeting also served to assure AIDL's commitment to helping the people of the Pine Ridge Reservation clarify their disability policies.

The Quad Squad was instrumental in coordinating the meeting; and provided technical assistance to project staff. Since they were established, and recognized as disability advocacy group representing the Oglala Nation, they contracted with AIDL to act as a liaison with the Tribe. The contract specified that AIDL would provide funding for coordination of the focus group, copying costs, facility rental, transportation expenses, stipends and per diem for participants (see Appendix D). Arrangements for the formal focus group, scheduled for September 1995, were set.

Focus Group

Local coordinators sent invitations to all tribal government departments and local service providers. Representatives from the Quad Squad, the Oglala Lakota Tribal College, IHS, CHR, the Tribe's Employment Rights Office, the Tribal Council and family members of people with disabilities attended.

Since the Tribe adopted the ADA as written, the original study guide did not fit the needs of the group. Their circumstances were beyond the initial steps outlined in the guide so the group moved forward to discussions about more significant, and practical, concerns.

The legal ramifications of the ADA were at the top of the agenda. How does the Tribe implement it? And the question of how to involve the Tribe as a whole versus the Quad Squad overseeing all disability issues was discussed.

Public Awareness and Education. An informal assessment was done and a number of questions came to the fore. How to educate the tribal community about disability and the ADA were discussed. There is a need to educate people about invisible disabilities such as hearing loss, diabetes, heart problems and arthritis, too. These conditions are often not associated with disability by the members of the Pine Ridge Reservation.

Since turnover and personnel changes are routine and customary within the Tribal Council and its departments, difficulties with keeping people trained on the ADA was discussed.

There is a need for culturally-relevant disability awareness training. A person may forgo use of a wheelchair due to the belief that something bad might happen for playing around with one.

Basic needs must be met before other issues can be considered: If you can't get out of your house because you don't have help, then you don't need to worry about handicap parking or curb cuts.

Funding concerns were of primary interest. How to raise money for the Quad Squad to continue their efforts to bring disability awareness to the reservations was discussed. And creative strategies for raising funds for adaptive equipment and independent living services were also discussed.

Policy Development, Recommendations and Impact

A successful disability resources fair was held on the Reservation. It led to the group adding to their list of goals. A tribal attorney is writing a set of handicap parking codes. Which tribal department will have responsibility for enforcement is still an unresolved question. However, the group is asking people with disabilities to get parking hangers and use them on the Reservation.

The group is in the process of making personal contacts to government facility managers to ask them to comply with the requirements of Section 504 of the Rehabilitation Act. They are planning letters to follow up the informal personal contacts.

The Quad Squad is currently developing a proposal for a planning grant with the Bush Foundation.

Fort Peck Reservation

About 6800 Assiniboine and Sioux people live on the Fort Peck Reservation with another approximately thirty-nine hundred tribal members living off the reservation. Assiniboine people speak a Nakota dialect and Sioux people speak a Dakota dialect, both are one of the five original Siouan languages.

The Fort Peck Reservation, founded in 1888, is in northeastern Montana, 40 miles west of the North Dakota border, and 50 miles south of the Canadian border. The Missouri River defines its southern perimeter. It includes more than two million acres of land.

The Reservation was formally established in 1887. As an example of the Federal government's policies described earlier, these tribes were forced to share a land based even though historically they were enemies. In 1934 the Fort Peck Assiniboine and Sioux refused the IRA, but continued to govern under a constitution written by members of the tribal government in 1927. A representative government that operates through a Tribal Executive Board was established in 1960.

Initial Contact and Tribal Authorization

Initial contact with the Fort Peck Reservation was made in May 1995 through informal discussion with the Tribe's Section 130 Project Director, who sits on the AIDL Advisory Board. He approached the Tribal Council in June to approve an invitation to the AIDL Project Director to present the Project to the Council. A presentation was made in July of 1995 and the Council, in turn passed a resolution that asked the AIDL for assistance in developing disability policy for their tribe. A meeting was scheduled for January 1996.

Focus Group

The first focus group meeting on the Fort Peck Reservation was held in February 1996. It was coordinated and arranged by the Tribe's Section 130 Project staff. Project staff requested, and received, permission to bring a representative of the state's assistive technology project (MONTech) to present information about technology and available services. Several Tribal Council members were invited and many issues of importance to the tribe were discussed.

Cultural and Personal Beliefs. The most often repeated belief is that all people deserve respect. Respect for others is a basic tribal belief and is an asset to the inclusion of all people in the society.

Some beliefs identified are personal, some are tribal and often they are not compatible with each other. An important example of these differences is the

concept of "living in two worlds" one traditional and based on the Tribe's culture, the other contemporary and based on U.S. culture. A person's beliefs can be a barrier to the acceptance of a disability.

Many of the participants believe that Indian people are losing their traditional ways by trying to integrate into the two societies. Some feel that by taking care of people we create a selfish "me" world. You only help people for the "pats on the back" you get, not for the simple sake of helping others. The help is given for the wrong world (reason).

Another belief expressed dealt with the traditional value of the old way of compassion. Statements such as, "When people need help, we help them"; "People should be cared for; it is part of the concept of extended family"; "Looking after others is natural"; "It is our responsibility to help others"; and "It is part of our culture" reflect this traditional attitude.

A good example of this living in two worlds might be the need to care for a person with a disability or an elderly member of your family. Although these two groups often have very different needs, the need for long-term daily care is present for both. Providing long-term daily care can lead to poverty for the whole family. Funding sources for personal assistive services often say that they cannot pay a member of the person's family to provide daily care. This leaves the caretaker few alternatives. A common solution is to apply for welfare services, which may keep the family in the system for life.

A "sandwich generation" has developed for many families living in two worlds. This describes the generation that is caught between the desire to care for their parents and the need to care for their children. The result is that very difficult decisions must be made. Often if the family is unable to take the person into their home, the only choice for caring for the elderly is to place them in a nursing home far from the family. This compounds the need for the adults in the family to work to provide a living for the extended family. Not using personal care assistance is a factor in burnout for many families caring for people with disabilities and the elderly.

Another traditional way is to "protect" people with disabilities - even if their behavior is wrong. We tend to allow them to do things that others would be shunned for, just because of their disability. This situation may also allow the individual to violate the rights of others.

Several people remarked that Native Americans are often ashamed of disability. A person with a legitimate disability may deny the situation as a result. Often a person will say, "I have a health problem" or that they have difficulty doing something, rather than stating they have a disability. "I just have a medical condition" or plainly, "It's not a disability" are sentiments that reflect this mind-set. Feelings of shame

produce an atmosphere that says "let's not talk about the issues because it's not expected of us." As a result, valuable services, for the person with a disability as well as their family, may be lost.

Some people with disabilities may not want to be identified because of the stigma attached to the words "disability" and "handicapped." Often people will avoid obtaining services for fear of being labeled.

A lack of education may contribute to the ignorant attitudes some traditional people may have about people with disabilities. Ignorance about what a disability is makes people feel a lack of respect for the person with that disability. This is often expressed in hurtful statements or attitudes.

Since speaking up about one's feelings is risky, these people usually go unchallenged about their hurtful, ignorant statements or attitudes. It is easier to go with the flow. But education about people with disabilities and disability issues in general may be a viable method for changing attitudes.

There is a belief held by many that people with disabilities should be taken care of; it is part of the concept of family. The type of help given is dependent upon the individual. Some people want to be catered to, some are independent, and some feel that others should wait on them.

There is also a belief among many that we have lessons to learn and that the disability may be is part of that lesson.

Acceptance of a disability takes time. There are several factors as to why this might be especially true for tribal members. The following are a few examples the group identified as to why Native Americans may have difficulty accepting a disability. The importance of changing this attitude was discussed at length.

One reason might be that because of the inclusive nature of the tribe, it is possible to live and adapt to a disability without acknowledging the disability. If the family takes the roles of caretaker, personal assistant and counselor, the person with the disability may not have to deal with their disability. They may not even realize they have a disability. This is not a bad thing in and of itself, but it often results in loss of services for the whole family.

Elders are "included" in a similar way. They tend to believe that it is natural for their bodies to slow down. Therefore, they do not seek assistance for aging problems that can often be treated. This is another large group that does not receive all of the services that they might need and that can improve their quality of life.

People with diabetes face similar problems. Because of the prevalence of this disease in the Native American population, developing it has become expected and therefore not recognized as a disability. Often people do not even seek medical care until the disease has progressed to the point that it threatens the person's life.

Role reversals within the immediate family may also occur as an automatic response for family survival. The people involved may not even know changes have taken place. Often the caretaker develops a disability that can be directly related to the care that was given. Sometimes this allows acceptance by the person with a disability to take years.

These issues may cause many people to avoid requesting and using needed services. Or family members take the role of care giver or personal care attendant and services are never sought. This lack of use leads to a belief by service provides that there is no need for their services. The result is that many people's needs go unrecognized and unmet.

This predicament was recently emphasized when the state's Self-Directed Care Program staff were in Fort Peck to talk about their services. They were told that there was no need for their services on the reservation. Members of the focus group were not aware of this program. However, they felt the services were both needed and wanted by individuals who lived on the reservation.

In 1992, there were 127 individuals diagnosed with traumatic brain injury (TBI) on the Fort Peck Reservation. However, it is important to note that there may be a much higher incidence of TBI than has been identified by the health system. Few victims of domestic violence or people who have been involved in a fight ever seek medical assistance for head trauma. Individuals who have suffered falls after drinking, been thrown from a horse, or been involved in auto accidents may also experience undiagnosed TBI. These cases may also be used to further support the need for this type of program.

A large group of people with disabilities are those who use a wheelchair for mobility. There are 47 wheelchair users on the Fort Peck reservation. Of these 47, the members could only identify about five whom they saw out in the community or at tribal functions. The group expressed concern as to where the other 40 people are and why they are not seen or heard from.

Another group of disabilities discussed were Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) and other learning disabilities. The incident of these disorders may be much greater than the number reported because often both mother and father abuse alcohol and/or drugs. Again, many Native Americans do not want to be labeled so they do not seek services. However, the Two Bulls Treatment Center is beginning to make a difference. Screening for these problems at an early

age by schools and health care personnel was advocated as part of the answer. The schools and the health care systems needs more education.

There appears to be a great void of information about not only disabilities but also funding for assistive technology and personal care services. Another gap appears to be the lack of knowledge about equipment and assistive devices available to a people with disabilities. These voids reduce the quality of life for people with disabilities and may prevent them from contributing to their societies in a positive way.

A repeated phrase was, "We need to educate the people about disabilities." While the tribe has tried to address these issues, it's attempts have been sporadic. The tribe often relies on the Section 130 Tribal Vocational Rehabilitation Project; at other times they have had no guidance. As an example, ramps are built too steeply with no way to get from the ramp to the parking area. Often individuals stated that they were unable to attend social events because of physical barriers that exist.

The needs of all tribal members must be addressed. One way to do this is through some form of resolution to protect the rights of tribal members.

A staff member from the Rural Institute on Disabilities' MonTECH Program was introduced. She provided an overview of the MonTECH Program. She outlined information about MonTECH: information and referral, funding coordination and advocacy, Access Cooperatives for Assistive Technology (ACAT), and the Equipment Loan/Lease Clearing House.

She also outlined other services available to the tribe: Montana Medicaid, Medicaid Optional Services, and Medicaid Home and Community Based Services. A matrix of Medicaid services and optional services was distributed to the focus group. A detailed presentation was presented on the following Optional Services through Medicaid: Personal Assistance Services (PAS), Home and Community Based Services (HCBS), Social Security Work Incentives and independent living services.

The group agreed to the nature and scope of the problem and quickly moved on to assessing needs in employment, access and transportation. A brief informal needs assessment was conducted in each area.

Public Accommodations and Access. The issue of access resulted in the group listing things that are available and the needs that have yet to be addressed. One recommendation is that some form of uniform codes be developed to which all entities must adhere when providing access. The Americans with Disabilities Act Accessibility Guidelines (ADAAG) were suggested as a model for these codes.

Employment. Tribal personnel policies were reviewed as part of this process. Suggestions were made that would modify the existing policy to become more disability-friendly. Only a few words needed to be changed.

Hiring practices, tribal applications and how to prevent the "screening out" of qualified tribal members, who might have a disability, from employment was also discussed.

The issue of shared responsibilities for purchasing needed adaptive equipment and who those entities are was next discussed. There are many avenues that can be explored to assist with this matter. The MonTECH representative stated that she would be available to assist with this problem.

Transportation. The Fort Peck Tribe has developed a fairly suitable transportation system. However, after discussing other issues, the group concluded that a needs assessment should be done to see if they might add to the number of vans available. The Government Services Administration (GSA) might be able to help with the purchase of another van, since they have helped in the past.

The group began planning how to organize to address these issues as a whole tribe so that not just one tribal department (the Section 130 Project) would hold sole responsibility.

The need for some form of committee or other type of group was discussed. A Task Force was deemed the most effective form of group. The Task Force is comprised of three subcommittees: access, employment and transportation. The Tribal Council has designated members from departments or agencies that will be affected by the issues the subcommittees' address to participate. Each subcommittee will then return the issues to the Task Force who will then take them to the Tribal Council for legislative action.

AIDL staff have made one follow up visit the Fort Peck Reservation to help develop a resolution to mandate the task force. The resolution will also require tribal departments to participate at the discretion of the task force.

Policy Development, Recommendations and Impact

The Task Forces' Subcommittees are currently meeting to address their areas of concern. And the Tribal Council has agreed that resolutions, sponsored by the Task Force and passed by the Council, be included in the Tribe's Comprehensive Code of Justice.

Nez Perce Reservation

There are roughly 3,000 Nez Perce people with about 1,500 living on the Reservation. They are considered Plateau Indian and speak a Sahptian language.

The Nez Perce Reservation, created in 1855, is located in the panhandle of Idaho. Bordered on the west by the Snake River and Washington state, it includes 92,685 total acres. Nearly thirty-two thousand acres are tribally-owned, over 59,000 are allotted and about 1,700 acres are owned by the Federal government. (Davis, et.al., 1994).

As with many tribes, the Nez Perce rejected the IRA. The Tribe's current constitution was adopted and ratified in 1948. The Nez Perce Tribal Executive Committee, whose members are elected at large, is the primary ruling organization. It directs and conducts tribal business improvement, human services and natural resources programs. The Tribe also has a General Council that has only limited powers.

Initial Contact and Tribal Authorization

A member of the Nez Perce Tribal Employment Rights Office (TERO) heard of the AIDL through a friend who had attended a presentation delivered by the Project Director. After he called and requested information about the focus group process, he presented the idea of a focus group to the Tribal Council's Health and Human Services Subcommittee. They agreed to present the idea to the full Tribal Council, who voted to approved the AIDL project's presentation. The TERO employee acted as focus group coordinator.

Focus Group

The meeting started with an overview of the American Indian Disability Legislation Project (AIDL). The history of the project and the results of the national survey were presented.

Representatives from the tribe's TERO office, Education Department, Indian Health Service (IHS) and Head Start were present. The General Council President, consumers and a representative from the Elders group were also in attendance. Additionally, representatives from Idaho's Tech Act project and the Disability Action Center (a local independent living center) were present.

Cultural and Personal Beliefs. General information on disability was shared and discussed. Several participants noted that education about disability makes you think more about disability. This idea was expressed in different ways by several people present. One individual said that until he learned about disability, he did not know

that he too, has a disability. He had always thought that you had to be in a wheelchair or confined to bed to be considered disabled. He not only had one disability but several. One individual talked about how you do not think about your grandmothers and grandfathers as having disabilities, but they do. There was discussion about a small boy who has spina bifida who can walk, run and play. The Tribe does not see this child as a person with a disability because he can walk and play. One person talked about how after their father had a stroke, the mother went to work and the father stayed at home and took care of the kids. This is an example of role reversal because of a disabling condition, however the Tribe just saw it as the normal way of things, expected by the society.

Disability awareness helps the Tribe, the people with disabilities and their families understand that they need more education. Awareness fosters the desire to provide services and to help with access and other needed things. Often in the past the family has just taken care of all of the needs of the individual. However if the family is unavailable or unwilling to provide the needed support there is no one to provide it. As an example ,a young man who had no family support became disabled. Because of the lack of support he turned to drinking and eventually died as a result. This is only one example of what can happen when there is no awareness of disability.

Education leads to a recognition of need. It is important to get more people involved. One individual felt that the level of ADA awareness for the Nez Perce Tribe, if put on a scale of 1-10, would maybe rank a two. The group felt that this was fairly accurate. Not only does this lack of awareness lead to apathy by the Tribe, but it also leads to a lack of services and accommodations. Even the person with a disability is often not aware of what they could have or expect from others. The group felt that it was important to educate not only the tribal leaders but all tribal people about disability. They expressed the need to get the information to the people. People with disabilities are not heard from.

People with disabilities may not receive the services that are available because of this lack of awareness. There is no word in the Nez Perce language for disability, only a word for weak mind (pel-pel). Traditionally families have taken care of their people to the best of their ability. The extended family was responsible for the person with a disability. They were included in activities and the family accepted their condition(s). There was no concept of being different. "Our grandfathers and aunts taught us acceptance. We were taught to respect and help anybody who needed help. This is how respect was taught."

Respect meant that you were willing to help without compensation because you wanted to and it was expected of you as part of the family and the community. "We were told you should listen to the disabled. Learn from them and respect them. We were taught that it was important to respect the disabled for whom they were and

include them as equals. Our aunts told us that we should not make fun of them or talk about them because the spirits could make the same thing happen to you."

Respect for yourself fosters respect for others which, in turn, brings you respect. "Our Tribe has a memorial honor dance. We are expected to take everyone who cannot go out by themselves and help them to dance, even if we have to carry them." This is one form of respect practiced by the Tribe.

Some members were taught that the person with a disability, especially a mental illness, are special. They are considered "gifts" and the Tribe is supposed to learn from them and protect them. Another individual talked about how horribly disabling mental illness is and how the lack of services provided by the Tribe has affected people with mental illness. One individual said that he was taught that the mentally disabled or mentally ill are "good luck" or a "gift to the community."

Another person talked about being taught that if the child was born with a disability, the disability was perceived of as being deserved. It was the fault of the parents; they did something wrong. There was some shame attached to the parents but not to the child. The child was accepted, included, cared for and respected.

Shame is often a frame of mind. It is a part of a person's own self-concept. People sometimes feel less than whole or human. The disability is a punishment for wrongdoing. They have a poor self-concept that fosters shame and leads to trouble with coping skills.

Many in the group feel that there is cultural change taking place. The extended family is not as important as before. An extended family support system is no longer the norm but the exception. "Our young people are learning to look out for #1, not their neighbor. There is a change from community to family and from family to individuals. This is not the old ways. We need to figure out how to return to the old ways of community.

"The old ways taught respect and acceptance of others. The whole neighborhood helped to raise the children. If one was corrected then all of the children that were involved were corrected and this fostered a sense of community for the young people."

The value and benefits of the extended family were many. Often the children were raised by their grandparents or their aunts. This allowed children to learn from many different people. "Our language was taught and spoken in the home. Now our Tribe does not feel that it is important to teach the children in our schools and Head Starts. This is a shame because if we lose our language we lose a part of our culture and who we are as a people. We need to find a way to regain what we have already lost and prevent losing of any more of our culture and beliefs."

One person talked about the progression of the old ways and how respect worked. Families took care of their own; the community took care of each other. Respect was earned by giving respect to others. "We need to get back to that way of living."

The group discussed spiritual unwellness issues. Many people, both people with disabilities and without, are spiritually unwell. Disability does not seem to make a difference. Anyone can be spiritually unwell at times. What is important, is how we deal with the unwellness. Some people are beginning to practice holistic wellness. This emphasizes the need to work on all aspects of ourselves. It deals with the whole person and teaches the participants how to become a complete person.

There is a need to use language that emphasizes the disabling condition as only a part of the person. The origin of the commonly used term "handicapped" comes from the idea of "cap in hand." The group felt that it was important to promote the use of correct and less negative terminology. An example might be to refer to a person with hearing problems as "a person with a hearing-impairment" not as "a hearing-impaired person." By putting the person first and the disability second you are reducing the disability to only a part of the person; the disability is secondary. Also, using phrases such as "wheelchair-bound" implies that the person is "bound" to the chair. When in fact, the term "wheelchair user" implies that the person is in charge of the chair and uses it for mobility purposes. Language can make a big difference in a person's self-concept.

The common belief was that all people should be respected for who they were, not what they have. All people are different and people learn differently. This is good, because if everyone was the same, it would be a very boring world. The Tribe encourages acceptance of, and respect for, these differences.

A primary need of the Tribe is education. The group felt that the entire Tribe needs to receive education about disability and the issues that surround it. What is most important, is the need to educate tribal members with disabilities so that they can learn what services they need and what is available. Often people with disabilities do not get necessary accommodations because they don't know what to ask for or how to ask for it.

One individual talked about the fact that their family did things for them that they could still do for themselves. This bothered them, but it is the way of the Tribe. The Tribe has built a house for them and they now live independent of their family with their children. This has made things much better. The house was designed and built specifically for this individual and their needs. The group did not know, however, if there had been other homes built or modified for persons with disabilities.

Public Accommodations and Access. There is a need for an assessment of the buildings the Tribe owns and the ones they have an interest in. This is important because most of the group members did not know what types of accommodations are in place and where improvements still need to be made.

This discussion lead the AIDL staff to ask what the Tribe has already done to make the Reservation accessible and what they plan to do. The Tribe has made many accommodations, but there are still some areas that need addressing. The areas that have been identified might be where the first accommodations are made. An informal needs assessment of access issues was conducted. The following were the findings and suggestions from those efforts.

What's Here

Ramps: Housing Authority building has ramp on front door only; Veterans Society, Head Start, IHS buildings have two ramps on each building. The Senior Citizen's Tobacco Line Fund funds housing renovations and building ramps for elders.

Tribal Council Chambers: These chambers are fully accessible without a raised platform as often happens. There is also a wheelchair accessible bathroom adjacent to the chamber.

Buses: The senior citizens have two buses that are lift equipped. These buses however, can only be used by the elders for their own activities. Other members of the Tribe are not allowed to ride the buses. One bus is in Lapwai and one bus is in Kamiah. There are two senior centers, one in each community.

Housing: The Tribe has built at least one fully accessible house. They have also built senior complex buildings that have apartments in both Lapwai and Kamiah. They are all one-bedroom, not sure how accessible they are for a person in a wheelchair.

What's Needed

Restrooms: The community centers in both Lapwai and Kamiah may need renovation.

Building Assessments: The Housing Authority, Fisheries, Tribal Court, ERWM, TERO, Forestry Building, Community Centers, Senior Centers, and others that the Tribe owns and/or manages need to be assessed for access.

Ramps: All buildings should have more than one ramped exit or entrance.

Universal Design: All new construction should be built with universal design in mind. This would allow for the implementation of accessibility accommodation at a later date.

Signage: Clear, uniform signs should be posted on all buildings and restrooms. Often the people do not know about the accommodation because of lack of signage.

Gaming Hall: The new gaming hall needs to be assessed for accessibility during the planning stage.

New Construction: All new construction should be built, at the very least, to the minimum standard of the ADA 's Accessibility Guidelines.

Employment. Employment issues were discussed next. The need for disability education for employers was discussed. Employers often fear that hiring a person with a disability will be costly because of providing job accommodations. Most accommodations, however, can be made for less than $100.

What's Here

Unemployment: The group estimated that the unemployment rate is 60% in summer and jumps to over 80% in winter months.

VR: The TERO office has an informal agreement with state VR to provide services to tribal members with disabilities. The closest state office is in Orofino.

Section 130: The Tribe submitted a proposal for a Section 130 project to the Federal government. The proposal was not funded. The group felt that the grant should be revised and resubmitted.

Tribe: The Tribe employs about 330 people. There is no break down as to how the people with disabilities are represented in this number. Some tribally-owned businesses are: Limestone Enterprises, Forest Products, Nez Perce Express, Warehouse Foods, and Young Horsemen (they have breeding stock and provide trail rides).

GATE: Gain Access to Employment is a program of Lewis and Clark College in Lewiston that administers an initial assessment to determine educational and/or employment readiness.

What's Here (Cont.)

Employment Readiness Center: Housed at the Lewis and Clark State College, the program offers a 7 week course on employment preparation. It also offers skills assessment and self-esteem building. This program is designed to take a person from "bare bones" to employability. Most participants are women who are referred through the Jobs Program of states' social services.

Title VI National Indian Council on Aging: A grant funded program that puts senior citizens to work at various locations on the Reservation.

TERO: The Tribal Employment Rights Office is an employment and training project. It is funded by the Equal Employment Opportunity Commission, JTPA, the Adult Basic Training Program, Idaho JOBS Program and federal contractors.

JTPA: Job Training Partnership Act project, housed with TERO, partially funds trainee employment.

What's Needed

Assessment: The group would like to do an assessment of their employment application and hiring policies.

Awareness Raising: The group feels that they need to provide awareness training for employers regarding costs of accommodations and sources for information about technical assistance.

Attitude: Awareness training for the whole community could bring about a change in attitudes.

Jobs: One strategy for employing people with disabilities and tribal people in general is for the Tribe to create its own jobs.

Transportation. Transportation needs were discussed next. There are many transportation needs on the Nez Perce Reservation. The group would like to see some improvements made in the area in the near future. It is a real problem as the Reservation communities are spaced 60 to 70 miles apart. This makes it difficult to provide services, coordinate functions or arrange activities because of the great distances that must be covered. The Tribe has developed services in both Lapwai and Kamiah to bridge the gaps created by distances.

What's Here

Buses: The seniors have two buses, one in Lapwai and one in Kamiah. These buses are lift equipped. However they can only be used by seniors for approved activities.

Other: The only other transportation for people with disabilities are family autos. Few have lifts or are equipped with hand controls.

What's Needed

Schools: The schools are state-owned and state-run. The group did not think that any of the buses are lift-equipped.

Head Start: The Head Start has vans but none of them are lift-equipped.

IHS: The Community Health Representative (CHR) Program have vans but none with lifts. The group will work with IHS to find accessible transportation for the CHR Program.

General Public: The group would like to see some type of public transportation system. There was a proposed transportation system from Kamiah to Lapwai but it has not been funded.

Maintenance of Existing System: Many tribally-owned vehicles have become unusable for lack of maintenance. A line item built into the tribal budget for upkeep of tribally-owned vehicles is a goal of the group.

GSA: The group will research the possibility of procuring vehicles from the GSA motor pool.

Policy Development, Recommendations and Impact

The participants recognized the need for a formal group to deal with the concerns raised. One criteria is that the people participating in the future must be people with conviction. And the group should be a grassroots movement from within the Tribe. Advocacy is an important issue. Training to help tribal members learn advocacy strategies might be a part of the educational process that group members design.

Access to all facets of life on the Reservation is another critical element. One way to address the accessibility issue is to do an assessment of all tribally-owned or operated buildings and programs. The group felt that the best way to accomplish this is to train someone from each facility to do the assessments of the buildings and programs. Each facility would then have their own disability advocate who is more aware of the issues and would have more "ownership" of the problems that need to be addressed.

Steps to Accomplish the Goal:

1. Send a memo to the people on the "wish list" and to the departments listed. Include a brief description of the group and what it hopes to accomplish.
2. Recruit and involve the senior community. It is a very important component of the makeup of the group.
3. Ask for volunteers to work on developing a mission statement for the group. This will help direct their efforts and assure that all members understand what it is that the group is trying to accomplish. The mission statement should reflect your ultimate goal; it should be long-term and achievable.

4. Take the mission statement to the Health and Human Service Subcommittee meeting at their second meeting in June.
5. Do an assessment of accessibility for all tribal buildings and programs.
6. Develop a presentation for the next General Council meeting in September. Possibly invite the AIDL staff to return at this time to assist with the presentation of materials to the General Council.
7. Develop other strategies that will include the most people in education and awareness building.

The makeup of the formal group was discussed at length. It was agreed that tribal employees, tribal leaders and people from the community at large should be involved. A list of tribal organizations that could provide essential support for the formal policy development group was developed.

Along with the AIDL presentation, staff members from the Idaho Assistive Technology Project and the Disability Action Center (a local independent living center) presented their programs. And as a result of the first focus group meeting, these local disability groups are now working more closely with the Tribe.

As of this date, AIDL the staff have not personally returned to this Reservation. Staff have retained contact via the telephone. The Tribe is developing a more formal group to address the issues that were raised at the initial meeting.

Discussion

These five case studies show that, in a surprisingly short period of time covered by this report, the use of the Tribal Disability Actualization process brought significant impact. It brought together a wide range of concerned tribal members, helped them identify many disability issues of importance and develop numerous suggestions for change. Each of the groups developed commitment and met repeatedly. Further, they have continued to meet since the formal end of this project. This study offers evidence of the effectiveness of a self-directed approach for tribes to develop disability legislation.

In addition, four tribal resolutions expressing support for disability issues and this procedure were passed, two policies or tribal government practices were actually changed, including the Confederated Salish and Kootenai Tribes' personnel policies. As such, they offer evidence in support of a self-directed approach for tribes in developing disability legislation.

The experience demonstrates that tribal governments can and will develop disability legislation and policy consistent with the ADA without the U.S. Government's intervention. In fact, these experiences show a high level of concern and commitment among leaders when disability issues are brought to their attention by tribal members.

The content of the group discussions presents an interesting mixture of issues. In all cases, issues specific to a particular tribe were discussed (e.g., the jurisdictional concerns of the people of the Flathead Reservation) but these varied across tribes. In addition, each reservation group discussed issues of universal concern to people with disabilities, such as physical access to public life. Even in these cases, however, there were often unique considerations, such as how the people of the Navajo Reservation can access personal care assistance even though they live in extremely remote areas.

In several cases, these differences present serious practical problems. For example, the tribe of the Assiniboine and Sioux people have large, extended families and deep cultural expectations for family members to provide care. Medicaid policy prevents any family member from receiving financial support from U.S. Government programs for providing personal assistance. Not only are there cultural expectations for family members to provide care but these families often live in rural areas where no one else is available to provide that care. This conflict can lead to family impoverishment or to institutionalization of loved ones in programs far from their homes and families. Such policies are subject to waivers and should be granted.

Several tribes' efforts in this process focused on deep considerations of the meaning of disability and its experience within the context of their tribe. These

groups had much to consider and did not move as quickly toward action as others. Their concerns included the potential of being labeled in a way that adversely affected them within the tribe or of speaking out (i.e., advocating) in a context that is less accepting of such action.

Others, notably the Assiniboine and Sioux spoke briefly about these issues but moved quickly toward action to solve problems. Such differences may be cultural between tribal groupings or may simply represent more familiarity with the issues and a readiness to proceed.

Additionally, many Indian people with disabilities, as with others in the broader culture, must live on subsistence income and cannot afford the added expenses required to take part in research or focus group activities. Future projects that conduct participatory research need to consider budgeting funds for stipends, honorarium, per diem and travel expenses to allow individuals to participate.

This is an approach to community development that is truly a rural response. It may provide a method of universal application because it offers the members of any community, no matter what size, the opportunity to review problems and develop solutions that meet their unique circumstances.

There are a number of limitations to this study. First, it's formative in nature. Little research has been conducted in this area, although those working with such programs as the Section 130 Projects recognize the tremendous needs and problems that exist. And the tribes themselves are just beginning to consider making formal legislative changes to benefit their members with disabilities.

Second, the process requires context-shaped procedures. Because of the uniqueness of each tribal group, efforts must be tailored to that individual tribe. Cultural considerations must be acknowledged and changes must abide with these societal concerns.

A third problem is the limited number of tribes that participated in the study. Many considerations such as the project's short time frame, limited funding for travel to reservations and the tribes' need for time to study the implications of disability policy issues all contributed to the limited number of participating tribes.

Finally, the format of this model does not allow for control. Since the focus groups are comprised of individuals interested in developing disability policies on tribal lands (e.g., service providers, tribal governmental department personnel and people with disabilities), there is no method of measuring their efforts against a controlled group.

Nevertheless given the wide-spread difficulty of seeing true implementation of, and acceptance of the spirit of, the ADA among the broader community, perhaps this approach by tribes offers a model that could be used in other combinations of place and interest.

The tribes that participated in the process have made significant headway toward educating their members about the needs of Indian people with disabilities. They have also recognized that their efforts must be consistent and on-going, and that funding and enforcement are key issues. A major barrier to the continuation of these efforts, and the expansion of this opportunity to other reservations, involves the question of who is responsible for directing and funding such activities. Most tribes lack the financial resources to mount a systematic effort to build tribal disability legislation. State governments have little responsibility and less authority on reservations. While some foundations have interest in supporting tribal development, they tend to focus narrowly on special issues or support only a few tribes.

Only the Federal government has the combination of authority, resources and responsibility in this area. Unfortunately, no federal agency has the duty to assist tribes in addressing this gap in disability law and policy. This situation must be clarified if American Indians with disabilities are to enjoy the same protections as their neighbors.

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Appendix A

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Southeastern Area
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Lumbee

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JoAnn K. Chase, J.D.
Mandan Hidatsa

Resolution # 94-DEN-HR/H-082

Title: American Indian Disability Legislation: Americans with Disabilities Act (ADA)

WHEREAS, we, the members of the National Congress of American Indians of the United States, invoking the divine blessing of the Creator upon our efforts and purposes, in order to preserve for ourselves and our descendants rights secured under Indian treaties and agreements with the United States, and all other rights and benefits to which we are entitled under the laws and Constitution of the United States to enlighten the public toward a better understanding of the Indian people, to preserve Indian cultural values, and otherwise promote the welfare of the Indian people, do hereby establish and submit the following resolution; and

WHEREAS, the National Congress of American Indians (NCAI) is the oldest and largest national organization established in 1944 and comprised of representatives of and advocates for national, regional, and local Tribal concerns; and

WHEREAS, the health, safety, welfare, education, economic and employment opportunity, and preservation of cultural and natural resources are primary goals and objectives of NCAI; and

WHEREAS, because the United States Congress excluded Indian lands (Federal and State) due to sovereignty issues.

WHEREAS, passage of this resolution would encourage Indian communities (reservations) to pass legislation or resolutions which would provide equal access to all Tribal members; and

WHEREAS, Tribes are excluded from the provisions of the ADA because of the tribes sovereign status, but this legislation does not prevent the tribes from providing equal opportunities to all tribal members: and

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WHEREAS, there is a need to establish disability legislation for American Indian tribes on reservation that is consistent with the principles established by the ADA and is respectful of tribal sovereignty and cultural diversity, and to do so by an alternative method other than the courts and tribes wishing to establish their own ADA legislation that will be respectful of tribal sovereignty and cultural diversity and yet address the issues of the ADA; now

THEREFORE BE IT RESOLVED, that NCAI does hereby endorse the project in its efforts by passing this Resolution of Support.

CERTIFICATION

The foregoing resolution was adopted at the 1994 Mid-Year Conference of the National Congress of American Indians, held at the Hyatt Regency in Buffalo, NY, on June 14-16, 1994 with a quorum present.

gaiashkibos, President

ATTEST:

S. Diane Kelley, Recording Secretary

Adopted by the General Assembly during the 1994 Mid-Year Conference at the Hyatt Regency Hotel in Buffalo, New York.

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Tesuque Pueblo

Anadarko Area
Sac & Fox

Billings Area
Chippewa Cree

Juneau Area
Yup'ik

Minneapolis Area
Ojibwa

Muskogee Area
Peoria

Nashville Area
Creek

Phoenix Area
Northern Ute

Portland Area
Spokane

Sacramento Area
Klamath (Illinois)

Southeastern Area
Lumbee

EXECUTIVE DIRECTOR
Marilyn Holmes

RESOLUTION # B-94-038

Title: Support For The Project On American Indian Disability Legislation: Toward The Development Of A Process That Respects Sovereignty and Cultural Diversity

WHEREAS, we, the members of the National Congress of American Indians of the United States, invoking the divine blessing of the Creator upon our efforts and purposes, in order to preserve for ourselves and our descendants rights secured under Indian treaties and agreements with the United States, and all other rights and benefits to which we are entitled under the laws and Constitution of the United States to enlighten the public toward a better understanding of the Indian people, to preserve Indian cultural values, and otherwise promote the welfare of the Indian people, do hereby establish and submit the following resolution:

WHEREAS, the National Congress of American Indians (NCAI) is the oldest and largest national organization established in 1944 and comprised of representatives of and advocates for national, regional, and local Tribal concerns; and

WHEREAS, the health, safety, welfare, education, economic and employment opportunity, and preservation of cultural and natural resources are primary goals and objectives of NCAI; and

WHEREAS, the recent passage of the Americans with Disabilities Act (ADA) has the potential to improve the lives of all citizens with disabilities including American Indians with disabilities living on reservations who may not benefit from this law because it specifically excluded Indian tribes from some of its requirements; and

WHEREAS, traditionally, the applicability of national legislation to tribal governments has been addressed through the courts, creating an adverserial approach which contributes to tension between tribal and other governmental entities; and

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WHEREAS, there is a need to establish disability legislation and educate all American Indian and Alaska Native tribal members that live on reservations that is consistent with the principles established by the ADA and is respectful of tribal sovereignty and cultural diversity; and

WHEREAS, there is and alternative method, otherr than the courts, for tribes wishing to establish their own ADA legislation that will be respectful of tribal sovereignty and cultural diversity and yet address the issues of the ADA; now

THEREFORE BE IT RE[illegible]ED, that NCAI does hereby recommend te endorsement and encourage the passag[illegible]merican Indian Disability Legislation as developed by each Tribe.

CERTIFICATION

The foregoing resolution was adopted at the 1994 Annual Convention of the National Congress of American Indians, held at the Sheraton Tech Center Hotel in Denver, Colorado, on November 13-18, 1994 with a quorum present.

gaiashkibos, President

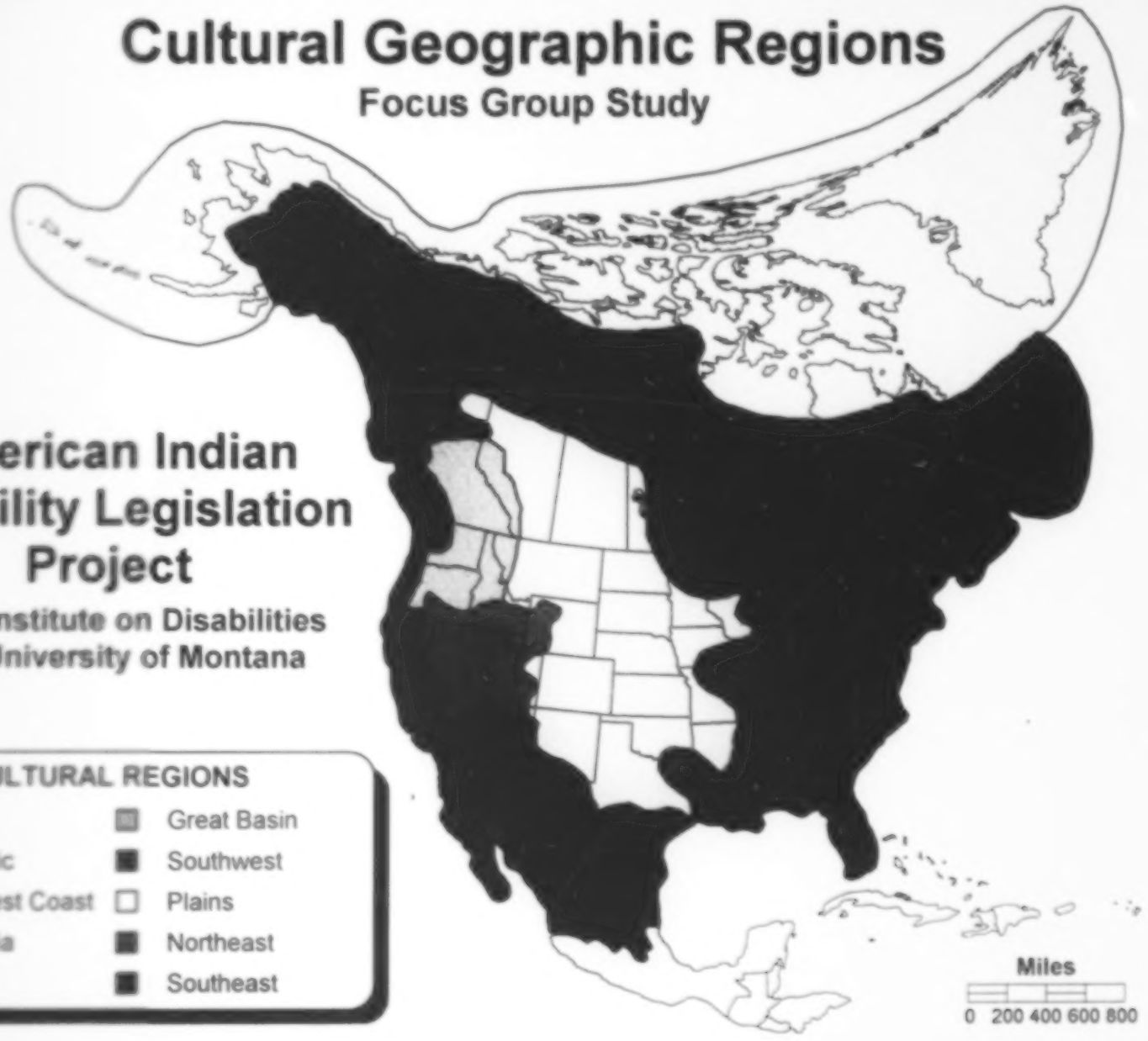
ATTEST:

S. Diane Kelley, Recording Secretary

Appendix B

Cultural Geographic Regions

Focus Group Study



American Indian Disability Legislation Project

Rural Institute on Disabilities
The University of Montana

CULTURAL REGIONS

- Arctic
- Subarctic
- Northwest Coast
- California
- Plateau
- Great Basin
- Southwest
- Plains
- Northeast
- Southeast

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Appendix C

ORDINANCE 69 - B

PERSONNEL RULES, REGULATIONS AND PROCEDURES MANUAL CONFEDERATED SALISH AND KOOTENAI TRIBES

M E M O R A N D U M

TO: Administration
Departments
Mission Valley Power
Salish Kootenai Housing Authority
Two Eagle River School
Sqelix'u/Aqłsmaknik Cultural Center
Salish Culture Committee
Kootenai Culture Committee
Legal Department

FROM: Katherine M. Teegarden, Personnel Director Katherine M. Teegarden

DATE: November 3, 1995

SUBJECT: Amendment 17 - Ordinance 69B

Enclosed is Amendment 17 to Ordinance 69B enacted by the Tribal Council on November 3, 1995. Please reproduce and disseminate throughout your department.

Filing Instructions

1. Remove existing page 10 (Chapter IV); insert new page 10
2. Remove existing page 12 (Chapter V); insert new page 12
3. Remove existing page 16 (Chapter VII); insert new page 16
4. Remove existing page 21 (Chapter VII); insert new page 21
5. Remove existing pages 23 and 24 (Chapter VIII); insert new pages 23 and 24
6. Remove existing pages 29 and 30 (Chapter XIII); insert new pages 29, 30 and 30-1
7. Remove existing page 36 (Chapter XIV); insert new page 36

Highlights of Changes

In Chapter IV, Section 13 - Rehabilitation Hiring is amended to include physical or mental impairment.

CHAPTER XIII

TERMINATION OF EMPLOYMENT

Section 1 - Resignation

Any employee wishing to resign shall file a written resignation with his immediate supervisor at least two (2) weeks before leaving. The resignation shall state effective date, reason for leaving, and a forwarding address.

Section 2 - Reduction-In-Force

When evaluating a reduction in force the Department Head must consider preference, qualifications, past performance and seniority.

Prior to taking action the Department Head shall submit written justification to the Personnel Director outlining factors considered and positions affected.

When at all possible the Department Head will give an employee who is affected by a reduction-in-force at least two (2) weeks notice, unless the Tribes and/or Department Head has no advance notice of discontinued funding.

Section 3 - Disability

An employee may be terminated for disability when he cannot perform the required duties because of physical or mental impairment. Department Heads are strongly advised to work with the Personnel Director regarding all cases of termination for mental or physical reasons to insure that proper medical evidence substantiates the termination. Separation due to mental or physical incapacitation will be made after exhausting all accrued compensatory, annual, and/or sick leave.

Section 4 - Termination for Cause

An employee may be terminated for cause by the Department Head.

A written statement of the reasons shall be submitted to the employee at the time of dismissal. Any of the following, but necessarily limited hereto, may constitute grounds for dismissal:

A. Incompetence or repeated neglect of duty.

B. Conduct which constitutes a clear danger to the orderly administration of the Tribal government.

C. Unauthorized absence.

D. Inciting or engaging in unlawful demonstrations, rioting, or civil disturbance.

CHAPTER XIII

TERMINATION OF EMPLOYMENT

Section 1 - Resignation

Any employee wishing to resign shall file a written resignation with his immediate supervisor at least two (2) weeks before leaving. The resignation shall state effective date, reason for leaving, and a forwarding address.

Section 2 - Reduction-In-Force

When evaluating a reduction in force the Department Head must consider preference, qualifications, past performance and seniority.

Prior to taking action the Department Head shall submit written justification to the Personnel Director outlining factors considered and positions affected.

When at all possible the Department Head will give an employee who is affected by a reduction-in-force at least two (2) weeks notice, unless the Tribes and/or Department Head has no advance notice of discontinued funding.

Section 3 - Disability

A. The Confederated Salish and Kootenai Tribes prohibits employment discrimination against "qualified individuals with disabilities". A qualified individual with a disability is: an individual with a disability who meets the skill, experience, education, and other job-related qualifications of a position held, and who with reasonable accommodation, can perform the essential functions of a job.

B. A person with a "disability" is an individual who:
- has a physical or mental impairment that substantially limits one or more of his/her major life activities;
- has a record of such an impairment; or is regarded as having such an impairment.

C. Persons who currently use drugs illegally are not protected when disciplinary/adverse action is taken because of the continued use of drugs. This includes employees who use prescription drugs illegally, as well as those who use illegal drugs.

D. Reasonable accommodation is any change in the work environment or in the way things are done that results in equal employment opportunity for an individual with a disability.

A supervisor must make every effort to provide reasonable accommodation to a qualified individual with a disability before considering termination.

Resolution No. 96-42

RESOLUTION
OF THE GOVERNING BODY OF
THE CONFEDERATED SALISH AND KOOTENAI TRIBES
OF THE FLATHEAD INDIAN RESERVATION, MONTANA

A RESOLUTION TO SUPPORT THE ESTABLISHMENT OF NEEDED ACCESSIBILITY TO NATIVE AMERICANS WITH DISABILITIES OR HANDICAPS.

BE IT RESOLVED BY THE COUNCIL OF THE CONFEDERATED SALISH AND KOOTENAI TRIBES THAT THERE IS A NEED TO PROVIDE ACCESSIBILITY TO NATIVE AMERICANS WITH DISABILITIES OR HANDICAPS:

WHEREAS, the Confederated Salish and Kootenai Tribes respect the lives of all of our people and recognize that our people is the most important Tribal resource; and

WHEREAS, the Confederated Salish and Kootenai Tribes, utilizing the authority vested in them pursuant to the Tribal Constitution, has authority to protect the health, security, and general welfare of the Confederated Tribes; and

WHEREAS, the Confederated Salish and Kootenai Tribes recognize the need for Tribal facilities, including recreational areas, pow-wow grounds and other Tribal areas that are operated and maintained by the Confederated Tribes, to be in compliance with the spirit of the American with Disabilities Act of 1990, Public Law 101-336 (104 Stat. 327) ("ADA"); and

WHEREAS, the Confederated Tribes recognize that no individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, and accommodations of any place of Tribal accommodation; and

WHEREAS, the Confederated Tribes further recognize that the objective of ADA is to provide mobility for disabled Americans and to enable them to lead normal and productive lives; and

WHEREAS, the Confederated Tribes are aware that an estimated 14% of the Native American population have disabilities and are prevented, and thus denied social and economic enjoyment taken for granted by others who have no disabilities, i.e., employment, recreational activities, etc.; and

WHEREAS, the Confederated Tribes are also aware that respondents to a recent survey of the American Indian Disability Legislation indicated that approximately 67% of the public buildings on the various Indian reservations are accessible leaving almost one-fourth of the public buildings inaccessible; and

WHEREAS, the Confederated Tribes have identified a need to develop a Tribal policy addressing the ADA to our present facilities, as well as any future (new or reconstructed) facilities; and

WHEREAS, the Confederated Tribes are in support of those concerned Tribal members who have formed a "Flathead Reservation Focus Group" for the purpose of creating awareness on issues affecting the handicapped and disabled Native Americans;

NOW, THEREFORE, BE IT RESOLVED, that the Tribal Council of the Confederated Salish and Kootenai Tribes recognize that our handicapped and disabled are entitled to accessibility to our Tribal facilities, recreational sites, pow-wow grounds and other Tribal areas.

BE IT FURTHER RESOLVED, that the Tribal Council of the Confederated Salish and Kootenai Tribes are committed to developing a Tribal policy to address and comply with the ADA.

AND BE IT FURTHER RESOLVED, that there shall be an established Committee to assist in the review process addressing the application of appropriate ADA accessibility guidelines.

AND BE IT FURTHER RESOLVED, that the Tribal Council of the Confederated Salish and Kootenai Tribes shall direct the Tribal Division of Lands and the Wildland Recreation Department, and any other Tribal department whose involvement will be necessary to address and meet the guidelines of the ADA and to participate in said Committee to ensure compliance.

C E R T I F I C A T I O N

The foregoing resolution was adopted by the Tribal Council on the 15th day of December, 1995, with a vote of 8 for, 0 opposed, and 0 not voting, pursuant to authority vested in by Article VI, Section 1(a), (f), and (u) of the Tribes' Constitution, with said Constitution adopted and approved under Section 16 of the Act of June 18, 1934 (48 Stat. 984), as amended.

Chairman, Tribal Council

ATTEST:

Executive Secretary

Appendix D

Description	Units	Each	Total
Coordination of Focus Group, September 22-23, 1995 Pine Ridge, SD	Fee	$2,000.00	$2,000.00
Expenses:			
Facilities - Quad Squad	2 days	$250.00	$500.00
Drivers-6			
Fee $50.00/day	2 days	$100.00	$600.00
Per Diem $25.00/day	2 days	$50.00	$300.00
Mileage			
Vehicle #1 (Rosebud)	230 miles/ day	$0.30	$138.00
Vehicle #2 (Martin)	90 miles/ day	$0.30	$54.00
Vehicle #3 (Martin)	90 miles/ day	$0.30	$54.00
Vehicle #4 (Kyle)	100 miles/ day	$0.30	$60.00
Vehicle #5 (Kyle) Large Van	100 miles/ day	$0.60	$120.00
Vehicle #6 (Pine Ridge)	150 miles/ day	$0.30	$90.00
Stipends	21 persons*2 days	$25.00	$1,050.00
Copying Cost	Fee	$34.00	$34.00
Total			$5,000.00

As per The University of Montana Independent Contractor Services Contract # 14447.

Lyle Bald Eagle, Coordinator - Quad Squad 4/25/95

REC'D 09/26/95 LC

ORDINANCE NO. 94-07

ORDINANCE OF THE OGLALA SIOUX TRIBAL COUNCIL
OF THE OGLALA SIOUX TRIBE
(An Unincorporated Tribe)

ORDINANCE OF THE OGLALA SIOUX TRIBAL COUNCIL APPROVING AMERICAN WITH DISABILITIES ACT (ADA).

WHEREAS, the U.S. Congress has adopted the Americans with Disabilities Act, and

WHEREAS, the HHS Committee of the Oglala Sioux Tribal Council does recommend to the Oglala Sioux Tribal Council the adoption of the provisions of the ADA in order to protect the rights of the Pine Ridge Reservation, disabled, now

THEREFORE BE IT ORDAINED, that the Oglala Sioux Tribal Council does hereby adopt the Americans with Disabilities Act (Attached here and incorporated by reference herein).

C-E-R-T-I-F-I-C-A-T-I-O-N

I, as undersigned Secretary of the Oglala Sioux Tribal Council, hereby certify that this Ordinance was adopted by the vote of: 13 for; 0 against; 0 abstain; 1 not voting, during a SPECIAL SESSION held on the 18th day of AUGUST, 1994.

Theresa B. Two Bulls

THERESA B. TWO BULLS
Secretary
Oglala Sioux Tribe

A-T-T-E-S-T

Mel V. Lone Hill

MEL V. LONE HILL
Vice-President
Oglala Sioux Tribe

RECEIVED
AUG 23 1994
Pine Ridge
Agency

Montana University Affiliated
RURAL INSTITUTE ON DISABILITIES
The University of Montana
Missoula, Montana 59812

BEST COPY AVAILABLE